

THESIS / DISSERTATION

AN INVESTIGATE OF FACTORS THAT INFLUENCE INTEGRATION OF PALLIATIVE CARE IN STATE HOSPITALS

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
CAPC	Centre to Advance Palliative Care
CEO	Chief Executive Officer
HIV	Human Immunodeficiency Virus
HPCA	Hospice Palliative Care Association of South Africa
HREC	Human Research Ethics Committee
ICU	Intensive Care Unit
NHI	National Health Insurance
NGO	Non-Governmental Organisation
NPFSPC	National Policy Framework and Strategy for Palliative Care
PC	Palliative Care
PHS	Public Health Strategy
WHA	World Health Assembly
WHO	World Health Organisation
UCT	University of Cape Town
USA	United States of America

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ABSTRACT

Background: Palliative care (PC) is considered a necessary component of care that needs to be integrated into the South African health care system, including hospitals. In South Africa there has been a growth in legislation and policy frameworks stating the need for and promoting the development of hospital-based PC programmes, however, how hospitals implement these policies is still unknown.

Aim: The aim of this study was to identify factors that influence integration of PC in state hospitals and develop implementation recommendations.

Objectives: The objectives of this study were (1) To describe existing PC services in three state hospitals in the Western Cape as perceived by the PC team; (2) To identify prohibiting and promoting factors in the integration of PC services in the three hospitals; and (3) To elicit views of health care professionals on how challenges to integrating PC in a hospital setting could be addressed.

Method: This was a qualitative study whereby individual semi-structured interviews were conducted with 17 key informants (five-seven at each hospital). To obtain perspectives from relevant professionals on an operational and management level, key informants included chief executive officers, nursing managers, PC programme managers, physicians, nursing sisters, pharmacists, and social workers. The data was recorded, transcribed and analysed through steps of thematic analysis.

Results: A description of each hospital's PC programme was provided. Prohibiting factors identified most frequently related to resource challenges (insufficient human resources, time for PC, infrastructure and funding), followed by the hospital culture (limiting attitudes and beliefs about PC), education and training (limited opportunity, time and funding), health care providers (lack of PC knowledge, communication and hierarchy), as well as patient, family, community, and policy factors. Enabling factors identified were mainly related to having adequate resources (PC champions, effective teamwork, infrastructure and financial support). Raising awareness of PC needs and benefits (using practical methods), education and training in PC (formal and informal training opportunities), support structures (self-care, management and government support), partnerships (networking), and community-based support were also identified as promoting factors.

Conclusion: Recommendations generated from this study were as follows: (1) Conduct a needs assessment to determine the organisations' readiness and needs for PC integration; (2) Identify PC champions who have an interest in PC and influence in the organisation; (3) Raise PC awareness by providing education and training opportunities, and making PC part of the hospital culture; (4) Ensure adequate amount and use of human and material resources for PC; and (5) Network and build partnerships with other organisations who already have PC services.

CHAPTER 1: INTRODUCTION

1.1 INTRODUCTION

With an ageing population and increased burden of disease, it is estimated that globally over 20 million people are in need of palliative care (PC) each year, with the majority in developing countries.^{1, 2} Given the ageing population and a rise in deaths due to non-communicable diseases, PC has been identified as a crucial component of care that needs to be implemented into the health care system, including hospitals.

This study explores factors that influence integration of PC in three state hospitals in the Western Cape. The research idea emerged from the researcher's professional (social worker) experience of working within a PC programme in a state hospital and was supported by a review of relevant literature. This chapter provides the relevant background that informed the research, by highlighting the world-wide burden of disease and the importance of PC within this context. It further highlights the importance of PC integration into the health care system (including hospitals).

1.2 WHAT IS PALLIATIVE CARE?

The term "palliative care" has been defined and redefined over the years but although variations of the definition still exist, the general ethos and goal remains the same.³ The World Health Organisation (WHO) defines PC as "an approach that improves the quality of life of patients and their families facing problems associated with life threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical and psychosocial".⁴

Palliative care represents a care philosophy (principles and attitudes), as well as an organised system for providing care that some believe complements curative interventions and others see it as an addition to standard care. Principles of autonomy, patient-centredness and seeing PC on the continuum of care are some principles, while practical care delivery focuses on having a structure, such as a multidisciplinary team, that supports certain activities, for example pain and symptom control, which requires relevant expertise (PC knowledge and skills) to target a client system (those identified in need of PC) with a desired goal to improve quality of life.³

Although there are varying perceptions of when PC should be offered in the illness trajectory (at diagnosis versus advanced stages of illness) evidence has shown that the earlier PC is introduced, the better the outcomes in terms of preventing and managing distressing symptoms as well as providing the needed support to patients and families.⁵

Palliative care is not limited to one place of care. A patient may need to be cared for at home, a frail care, health facility, or at a variety of places in the course of his/her illness, depending on the patient and family's needs and preferences and access to care services. This highlights the need for PC to be viewed and practiced on a continuum, which requires collaboration and coordination between professionals as well as mobilisation of resources at different health settings, as well as in the community.

1.3 THE NEED FOR PALLIATIVE CARE

Studies have shown that determining the prevalence of life-threatening diseases has been useful for understanding the need for PC and which diseases have PC needs. Although identifying PC needs in diverse segments of populations is vital for future planning in PC, studies have been somewhat hindered by unclear "population indicators". One of the reasons that these indicators are difficult to define is because of shifting perceptions of the PC field as discussed briefly in the previous section. An example relates to the question of who needs PC? Initially PC was associated with cancer but it has now been extended to "patients with any life-threatening illness, from diagnosis onwards"^{6(p1148)} For this reason, documenting causes of death linked to the need for PC has been one way of identifying those in need of PC.

In 2016, 56.9 million deaths were reported globally. Over 50% of these deaths were as a result of non-communicable diseases. Strokes and ischaemic heart disease were noted as the world's leading causes of death. Other diseases such as chronic obstructive pulmonary disease, lung cancer and diabetes mellitus each accounted for over 1.5 million lives, and mortalities as a result of dementia doubled since 2000, now resulting in dementia being the fifth most common cause of death in the world. Communicable diseases such as lower respiratory infections, diarrhoeal-related illnesses, and tuberculosis are still in the top ten global causes of death. HIV/AIDS' death rates have decreased and no longer present the same threat as it did in the past. These deaths are from causes that would benefit from PC. Deaths from road accidents are also one of the top ten causes of death in the world.⁷ Although this is a sudden death, not requiring PC for the patient, families would benefit from bereavement care. It is important to note that estimates of the need for PC do not include family needs.

In Africa, the AIDS epidemic has placed strain on the health system and the resources available to provide PC.⁸ With an increasing amount of patients reported to have chronic illnesses often marked by months or years of being ill with acute exacerbations,⁹ this poses not only great distress for the patients and families, but also a burden on the health system, with increased and lengthy hospital admissions, and increased financial implications.¹⁰ Although cancer and HIV/AIDS have been the main focus of attention

for PC intervention in sub-Saharan countries,¹¹ there is also an increasing need for PC services to be provided to patients with other life-threatening illnesses such as non-communicable diseases.⁹

In South Africa, Statistics South Africa's most recent data reflects 456 612 registered deaths in 2016, 48 141 of those deaths in the Western Cape.¹² Statistics also show that deaths are occurring in the later years in life, suggesting an ageing population, with most of the reported deaths being due to natural causes (88.8%). Results show an increase in chronic illnesses since 2009, with 2016 marking the uppermost figures. Although deaths due to chronic illnesses have increased, tuberculosis remains South Africa's principal reason for mortality (6.5%) followed by diabetes mellitus (5.5%), then heart and cerebrovascular diseases. Deaths caused by HIV takes fifth place.¹² The health system is therefore required for acute and chronic illnesses, and should be responsive to patients' needs.

Determining the factors that influence where a person dies is important for understanding care needs and for future health care planning.¹³ Various studies highlight demographic factors, types of illness and trajectories, availability of health services, social support and preferences for place of death as factors influencing whether a patient dies at home or in hospital.^{13,14, 15} Although research suggests that PC provided in the home setting is cost-effective, results in greater patient satisfaction,¹⁶ and is generally the preferred place of care and death,¹⁷ studies also highlight an increase in hospital deaths. Hospitals have increasingly been the place of death for many people with serious illness, often with their care needs being unmet.¹⁸

A study was conducted in Belgium looking at deaths in 2001, showing that 53.7% deaths occurred in hospital, 24.3% were home deaths, and 19.8% deaths occurred in care homes.¹³ Another study conducted in England and Wales – looking at past trends and future projections (1974-2030) of where deaths occur – show a decline in home deaths. Statistics South Africa's results for 2016 suggest that 47.5% of deaths occurred in health care facilities, with 43.2 % of those deaths in hospitals. 22.6% of deaths were home deaths, and 23.2% of deaths were not specified. These statistics show a decrease in home deaths and an increase in hospital deaths, which implies a greater burden placed on in-patient facilities. This will necessitate either a growth in in-patient facilities, or strengthening of community and home-based services or a combination of the two.¹⁴

Deaths that occur in hospital appear to be associated with the following factors: Limited out-patient support; inadequate care at home due to being alone or living with a spouse; fear of dying alone; and the patient's perception of being a burden at home.^{13, 15} Other factors that relate more specifically to patients who wanted to die at home but ended up dying at hospital, included distressing symptoms that could not

be managed adequately at home; family conflict; carers' inability to continue to provide care with the increasing care needs; home conditions being unconducive to care needs; and patients dying in hospital unexpectedly while there for a respite period.¹⁵

Whether a patient is admitted with a chronic illness and is discharged back home to live another year, or a patient is actively dying in the hospital, access to PC in the hospital is of vital importance. Various studies have been conducted in hospitals that indicate PC needs in hospitals. In Europe, the need for PC in hospitals is well recognised, and in Africa, although still in early stages, this evidence-base is growing.^{19,20,21,22} Past research highlights the prevalence of pain and distressing symptoms experienced by patients in the hospital setting.²³ Most people living with a severe illness will visit or be admitted to hospital during the course of their illness; possibly on several occasions. However, few hospitals have the necessary resources and systems in place to identify which patients need PC.

In a survey study conducted by Stuart-Clark et al.²⁴ at a large hospital in South Africa, the findings suggested a high mortality rate (42%) of patients admitted to the wards as well as a substantial readmission rate (20%) due to deterioration, highlighting a large amount of patients in need of PC in the hospital setting. In a cross-sectional, point-prevalence study conducted by Van Niekerk et al.,²⁵ a standardised PC identification tool was used to evaluate the need for PC among inpatients occupying acute beds in eleven state hospitals in Cape Town, South Africa. One in every six patients were identified as having a life-limiting illness which required PC.

Although the need for these services in hospitals has been identified, the start-up, growth and sustainability of such services is a major challenge.¹⁸

1.4 INTEGRATING PALLIATIVE CARE INTO THE HEALTH SYSTEM

A survey conducted in 2008 investigating the development of PC in 234 countries, showed that the majority of countries had evidence of only “localized provision” of PC. Four African countries (including South Africa) were considered to be in the “approaching integration” category, where PC showed signs of being integrated into the broader public health care system.²⁶ South Africa has already achieved a great deal with regards to the development of PC facilities.¹⁰ With PC being acknowledged as a basic human right, development in this area has been ongoing in this context. Initially non-governmental organisations (NGOs) such as hospices were the main providers of PC, but more recently an increasing number of hospitals have shown interest, and started developing their own services in response to the evident need.²⁷

Despite this notable development of PC, the World Health Assembly (WHA) identified various issues facing the health system which impact on the delivery of PC. Global challenges include the availability of essential PC medicines, socio-economic challenges, and lack of PC education throughout the health system.²⁸ In view of the need for PC integration, various organisations and councils have included PC in their strategies towards improving health care. At the WHA held in May 2014, Resolution 67.19 was adopted, urging member states to integrate PC services into their health care systems.

In 1990, the WHO introduced a public health strategy (PHS)²⁹ to integrate PC into health systems. For PC to be integrated successfully the strategy advocates that four components be addressed, namely: 1) Policy support; 2) Availability of essential medications; 3) Education and training in PC; and 4) Implementing PC at all levels. This model suggests that policy and drug availability issues be addressed first, followed by education and implementation. PC policy support is central to the successful development and sustainability of PC. The WHO PHS highlights the need for the following policies:

“Laws that acknowledge and define that PC is part of the health care system; national standards of care describing PC; clinical guidelines and protocols; establishment of PC as a recognized medical specialty/sub-specialty; regulations that establish PC as a recognised type of health care provider with accompanying licensing provisions; and a national strategy on PC implementation.”^{2(p27)}

Access to essential PC medications is another component of the WHO PHS. This component emphasises the need to evaluate the need for opioids, ensure affordability, and enable appropriate prescribing policies and procedures. The education component of this model acknowledges the need for and promotes PC education and training in the development of PC experts, and in educating caregivers, which should be introduced and supported in the media, tertiary education and continuous professional development. And lastly, implementing PC involves identifying leaders and developing implementation strategies. All four of these components are considered important in integrating PC into the health system, including hospitals.

In South Africa, the South African National Health Council has recently approved a National Policy Framework and Strategy on PC (NPFSPC).³⁰ This policy outlines the legislative and policy frameworks that support the integration of PC into the health system. These include: The WHA Resolution 67.19; the United Nations Convention on the Rights of Persons with Disabilities; the Global Action Plan for the Prevention and Control of Non-Communicable Diseases 2013-2020; the Constitution of the Republic of South Africa (Act No. 108 of 1996); the National Patients’ Rights Charter; the Medicines and Related

Substances Act, 101 of 1965; The Nursing Act (33 of 2005); and the National Development Plan 2030. The National Health Insurance (NHI) Service Package also promotes hospital PC, stating that service coverage includes that of PC services.

This NPFSPC aims to further improve the availability of PC services and is a significant step towards providing PC in the health sector in South Africa. To address identified challenges related to service delivery, education and training of health care providers, availability of data, funding, and leadership and governance, this policy framework highlights five principal goals. These goals to: 1) Strengthen PC on the continuum of care, 2) ensure PC education and training for all health care providers, 3) establish sustainable monitoring and evaluation structures, 4) ensure necessary funding, and 5) strengthen leadership structures to support application of PC policies.³⁰ Although these goals provide a comprehensive strategy for improving PC, to meet the desired outcomes it sets out to achieve, practical implementation of the policy is key. This requires an understanding of what promoting and prohibiting factors influence implementation.

Recently various role-players in the Western Cape have collaborated and formed a task team for PC. This development acknowledges and formalises the efforts of role players which is a systemic approach to PC integration. The task team developed a proposed model for the implementation of PC in this province, with the emphasis being on providing a continuum of care alongside other interventions. This model proposes that through policy, education and training of health care professionals, and funding, PC can be successfully integrated into the Western Cape health system. The model outlines what services, staff and level of training is required, and suggests the use of a “Twinning” strategy where hospitals that currently have PC services can link with those that do not. Potential challenges are that this model requires a fair amount of funding to implement PC as well as staff to forfeit fulfilling their own clinical duties to train others.³¹

The development of PC has seen a rise in hospital-based PC programmes in various parts of the world. Goldsmith et al.³² define hospital-based PC programmes as:

“an organized program providing specialized medical care, drugs or therapies for the management of acute or chronic pain and/or the control of symptoms administered by specially trained physicians and other clinicians; and supportive care services, such as counselling on advanced directives, spiritual care, and social services, to patients with advanced disease and their families.”

(p1095)

These authors further note the irrelevance of who provides the service, for example hospice or hospital staff, as long as it serves hospital service users.³² Research has shown that having PC services in the hospital setting can reduce costs, reduce hospital admissions, improve quality of care and also serve as an opportunity for education and training.¹⁸

In the United States of America (USA) there has been a rapid increase of PC services in hospitals. The Centre to Advance PC (CAPC) has assisted in developing these services and in so doing has identified hindering and promoting factors as well as key operational features needed for PC programmes to be developed and be sustainable.¹⁸ These operational features are considered to be essential for the sustainability of high-quality PC services in the hospital setting. Although these features look clear on paper, practical implementation poses a challenge. To develop such features, an understanding of what hinders and promotes PC integration into hospital settings is therefore crucial.

The key operation features identified by CAPC are: a) Programme administration - being visible in the management structure of the hospital by having a programme manager/leader and by having “routine reporting and planning that is integrated into the hospital management committee structure”,^{18(p1193)} b) Types of services - in-patient consulting services, out-patient services, and geographic in-patient units; c) Availability - routine and emergency services being available; d) Staffing - a multidisciplinary team being available (doctor, nurse, social worker, chaplain and mental health workers and psychologist or psychiatrist); e) Measurement - evidence of the value of PC services to patient systems and health care providers; f) Quality improvement - accountability and quality assurance, g) Marketing - making services known to stakeholders; h) Education - providing education and awareness to improve knowledge and skills; i) Bereavement services – follow-up telephonic consults, letters or cards, and mobilising necessary resources; j) Patient identification - screening criteria; k) Continuation of care – care pathways; and l) Team wellness – activities, debriefing, and burnout prevention.¹⁸

Research published in Canada in 2008 revealed that 21% of patients equated for the hospital costs in the last six months of life, and 24% of patients equated for days spent in hospital.³³ Hospital-based PC consultation teams have been reported to reduce hospital costs.³⁴ Hongoro et al.³⁵ conducted a cost analysis on a hospital-based and outreach PC programme in an Academic Hospital in Johannesburg which revealed that the average cost per patient per day was double the amount of the cost per outreach visit. In another study conducted in a Johannesburg hospital, Kirk and Collins³⁶ set out to assess the difference in quality of life of patients referred to the hospital PC team to those that were not referred. It was found that those referred to the PC team had better quality of life.

Few facilities in South Africa provide consistent PC and those that do have developed their services informally, usually initiated by passionate individuals with no policy guidelines to assist them.²⁷ Very little research has been conducted on the integration of PC services into government hospitals in South Africa. However, in an article by Gwyther et al.,³⁷ the growth of PC services in state hospitals in the Western Cape was reviewed in light of the recent approval of the NPFSPC. The Hospice PC Association of South Africa (HPCA) has developed structures and processes for the development, strengthening and accreditation of PC services within its members, which could be expanded and applied to the broader health care system. According to Gwyther et al.³⁷ a significant promoting factor in relation to hospitals is that hospices throughout the country have been points of referral. This extension of PC into the community and into homes allows for earlier discharge from hospitals.

Different models of PC have been developed according to specific needs identified for institutions and communities in South Africa. These approaches to developing PC were founded on research which provides evidence of the benefits of having hospital-based PC.³⁷ The following discussion focuses on some initiatives in the Western Cape.

In 2009 a PC programme was initiated at a district hospital in Cape Town in view of observed needs experienced by patients with advanced organ failure. In 2014 DesRosiers et al.¹⁰ conducted a study at this hospital to evaluate the extent to which the existence of the hospital-based PC programme reduces admissions and increases home deaths compared to standard hospital care. Medical records of a group of patients that died prior to the PC programme development were compared with a group of patients who died while the PC service was available to them. They found that there were fewer readmissions and more home deaths compared to standard hospital care. This study also pointed to the increase in referrals to the PC programme over several years, suggesting the potential cost benefits of such a service and an increased awareness about PC and health care provider “buy in”. In another study conducted at the same institution, Hunter et al.³⁸ conducted a study to determine the benefits of the hospital PC programme for patients with chronic heart failure. The findings suggested that patients’ symptom management improved while being enrolled in the programme, highlighting the benefits of having a hospital-based PC programme.

After realising the need and benefits of hospital-based PC, PC was initiated at Groote Schuur Hospital in 2011. Gwyther et al.³⁷ report that this initiative has increased knowledge and skills in PC and has promoted the nurse’s role in leadership. Nurses in the hospital are also reported to be optimistic about the development. Due to the success of the initiative and previous research revealing benefits of such

services, Groote Schuur Hospital was granted funding for a permanent PC team which now comprises two nurses (PC trained), two auxiliary social workers, volunteers who offer existential support, and medical staff affiliated to UCT Division of Family Medicine. In 2016, 79 referrals to PC per month were recorded, once again highlighting that the service is being acknowledged as being necessary and is being used.

In another study conducted to evaluate a hospital-based PC programme at Groote Schuur Hospital in Cape Town, Robertson et al.³⁹ highlighted that although this programme referred to their service as 'PC' which covers a broad spectrum of care, their service appeared to be primarily end-of-life care, or terminal care, suggesting that PC in hospitals means one has to be close to death. The irony is that many of the patients admitted to this hospital requiring PC during this period were discharged, highlighting that PC care in hospitals is not only about end-of-life care. This again emphasises the need to consider PC on the continuum of care. Regardless of where patients' preferences are to die, comprehensive care should be provided on a continuum, and according to each patients' unique needs and circumstances, and where patients present in need of care; even if it is at an acute hospital. In the next chapter, a review of literature on factors influencing integration of PC into health settings will be discussed.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

Chapter two provides a review of literature, drawing on relevant international and national studies that identify barriers and enablers to integrating PC. This review explores and critiques research already done in the field, provides clarity on related concepts, identifies gaps in the research, and brings focus to the research problem.⁴⁰

Online search engines used for key term searches included: Google Scholar, Elsevier, Medline, EBSCOHost (Africa Wide, Cinhal and Health Source), PubMed and SCOPUS. Additionally, other sources consulted included online journal articles and grey literature such as recent global and government policies, guidelines and other relevant documents. The literature review process employed in this study involved the exploration and critical evaluation of global and South African literature related to the research topic. The following key terms, and a variation of these terms were included in the literature search: “Factors”, “Promoting Factors”, “Enablers”, “Facilitators”, “Prohibiting Factors”, “Challenges”, “Barriers”, “Obstacles”, “Integration”, “Implementation”, “Palliative Care”, “Palliative Medicine”, “Hospice Care”, “Terminal Care”, “End of Life Care”, “Hospital”, and “Hospital Setting”. The term ‘Palliative Care’ acted as the link term in the searches conducted.

Due to there being little existing information on factors that influence integration of hospital-based PC services, this review was extended to include other health care services such as nursing homes and health care centres, looking at factors influencing the development and/or improvement of PC services.

2.2 FACTORS THAT INFLUENCE INTEGRATION OF PALLIATIVE CARE IN HEALTH SETTINGS

The following section provides a selected review on studies conducted in the USA, Europe, and Africa that highlight factors that influence integration of PC in health settings. The findings of these studies will be presented within the WHO PHS framework discussed in the previous chapter. It should be noted, however, that factors that influence the development and delivery of PC often overlap and therefore run across categories, and that authors often categorise these factors in different ways. To address this challenge and tension, the researcher will identify the factors addressed under each of the four WHO PHS categories and will attempt to focus on the way in which these factors emerge within the category concerned.

2.2.1 Education of Health Care Providers and Service Users

In a study by Sommerbakk et al.⁴¹ conducted in Norway in 2012, 20 staff members (managers and health care providers) working in health care facilities (two hospitals, one nursing home and two local medical centres) were interviewed individually, dually and via focus groups, to determine obstacles and enablers for improving PC relating to cancer and dementia. This was done through the evaluation of various PC implementation strategies, also known as improvement projects. Although generating comprehensive data on many different factors, various limitations of the study were noted. Those conducting the research were not trained in PC and were considered “outsiders” which may have limited the researcher’s ability to further explore certain factors. Also, the study was conducted in only one region in Norway, questioning whether saturation was reached. The interviews were conducted retrospectively, potentially introducing recall bias. Strengths of the study were the use of individual interviews and focus groups to support one another which validates the information and potentially obtains even richer data than if only one method was used. Although identified as a potential limitation, the researchers being “outsiders” could also be viewed as a strength as this addresses bias and potentially results in more openness to new views. Also, conducting the study at different types of facilities could reflect challenges and enablers at different levels of care.

Lack of PC knowledge and skills of health care providers was emphasised as a barrier by numerous participants according to Sommerbakk et al.⁴¹ Nurses reported feelings of anxiety about caring for patients who were terminal and reported that education in PC would be instrumental in improving their confidence. Knowledge and skills obtained by long-standing staff members was identified as a major facilitator, as staff had the opportunity to develop the expertise and avoid obstacles. Having staff members with PC expertise facilitated in-house PC conversations and teaching.

In another study conducted by Aslakson et al.⁴² in 2009 in a teaching hospital in USA, 32 surgical intensive care unit (ICU) nursing staff were interviewed via focus groups to obtain their perceptions on the barriers to provision of PC and optimal communication with regards to prognosis in their ICU setting. One of the limitations of this study is that opinions of staff working in other settings, such as emergency or medical departments, may have differed. Also, data was captured through note-taking rather than audio-recording, possibly affecting accuracy of data captured. Aslakson et al.⁴² also highlighted the lack of PC knowledge and skills of health care providers as a barrier and further noted how failure to recognise the end-of-life phase and an over-focus on curative interventions was partly due to a lack of PC education. Other barriers linked to lack of education were related to inadequate communication between health care

workers, discomfort of having end-of-life discussions, limited knowledge of existing resources resulting in limited explanation of care options, and lack of training in end-of-life care. Other barriers included perceptions of health care workers that death equals failure, matters around autonomy, contrasting beliefs regarding appropriate treatment and dying, and different understandings of terms such as “natural death” and “futile treatment”.

2.2.2 Training in Communication Skills

Poor *communication* with patients and families as a result of a lack of PC knowledge and skills was reported as a barrier to implementing PC in a study conducted by Cornetta et al.⁴³ in 2012 to assess the PC services in a teaching hospital in Kenya. Ten members (multidisciplinary professionals) of the PC team were interviewed to obtain their views of the barriers and the facilitators of their service. Although the participants represented various disciplines, one limitation of this study could have been not having the voice of management personnel in that particular hospital, as well as patients and families. However, a strength was that the participants were part of the PC team and could therefore be considered key informants on the subject. Factors prohibiting implementation included in this study related to barriers to accessing strong analgesics, difficulties in communicating poor prognosis to patients and families, poverty of families, and religious barriers such as beliefs about pain management and death. A lack of education and training in PC was identified as a barrier when it was noted that pain management was inadequate in 66% of in-patients in 2011. Since then education and training has become a major priority in ensuring quality PC in the institution.

Aslakson et al.⁴² also emphasise effective communication as a central factor in implementing PC in hospitals. Findings highlight logistical factors as barriers to communication as poorly timed ward rounds, unavailability of staff, meeting interruptions and limited time for difficult conversations. Aslakson et al.⁴² suggest that challenges relating to communication, especially with regards to breaking bad news, included families not attending meetings to avoid “bad news”, families having false hope, doctors giving false hope, undefined roles with regards to who of the professionals initiates difficult discussions, and unclear goals of care. There was a perception that doctors did not set up family meetings, rushed discussions, and therefore did not conclude conversations with staff and family members (leaving many questioned unanswered or not providing the opportunity for questions). Families were reported to be ignorant of the diagnosis, what resources were available to them, and of the channels of communication to follow. These factors, as well as communication challenges between professionals such as conflict

regarding ideas of prognosis between health care workers, discrepancies in communicating prognosis, and overlapping roles, were all perceived as challenges relating to a lack of PC education and training.

In another study, communication challenges between professionals were also highlighted as barriers. Smith et al.⁴⁴ conducted a study in two academic emergency departments in Boston to assess the attitudes, experiences, and beliefs of emergency care providers about PC in the emergency department. The study used three focus groups with 26 professionals (14 doctors, 6 nurses, 2 social workers, and 4 technicians). This method appeared appropriate for the aims of this study which was to elicit attitudes, experiences and beliefs; however, the limitations of using only focus groups are also relevant here. The variances between information gathered from a group and individuals can influence the analysis and understanding of the data, and having a supporting method strengthens the reliability and validity.⁴⁵ Including a variety of professionals (nurses, doctors, social workers and technician) as participants reflected views from people with different skill-sets and lenses which could be considered a strength of the study. Communication challenges between professionals working with outpatients versus those in the emergency department were highlighted in this study. It was reported that insufficient communication resulted in futile interventions that did not reflect the preference of the patient and family as well as conflict around withholding life-prolonging treatment. Insufficient training in managing pain was also noted.⁴⁴

Another study that emphasised communication as an important factor in implementing PC in hospitals was by De Kort-Verhoef et al.⁴⁶ who conducted a mixed-method study in the Netherlands to explore general practitioners' perceptions on how to avoid hospital admissions at end-of-life. The focus of this study was to determine if and how hospital admissions could have been circumvented and the barriers in relation to this. The first phase involved distribution of questionnaires to 319 general practitioners, followed by in-depth interviews with 18 general practitioners. Using a mixed-method approach for this study could be viewed as a strength. Surveys were distributed to a large sample of participants, and then the information confirmed with in-depth interviews with a portion of them. The findings of this study revealed that 24% of the participants who participated in the survey study reported that their most recent patient dying in hospital could have avoided hospital admission if there had been better communication with the patient, and better communication between professionals regarding the treatment plan. These findings were confirmed by the interviews with the 18 general practitioners. The interviews also highlighted communication timing, difficulty in relaying information in stressful situations, and patients and families limited awareness that the patient was dying, as further barriers.

Aslakson et al.'s⁴² findings of barriers include patient and family factors considered to be related to a lack of awareness and education in PC. These factors included the patients' and families' lack of knowledge and understanding regarding ICU equipment, beliefs that PC meant end-of-life care, and families not following proposed PC plans due to distressing symptoms resulting in readmission to emergency departments despite efforts to prevent this.

In view of the communication challenges experienced by health care professionals, Ganca et al.⁴⁷ conducted a study in a state tertiary hospital in Cape Town, where 14 individual interviews were conducted with doctors to “explore communication skills and practices when conveying a poor prognosis to patients and families, and to identify their communication skills, needs and understanding of PC”^(p940) Findings of this study highlighted issues relating to health care providers' and patients' perceptions of PC, difficulties in communicating poor prognosis, and inadequate pain management. This study highlighted that having hospital-based PC teams in state hospitals provides support for patients and doctors handling difficult conversations, and that the need for PC education and training to improve communication should be addressed.

The above-mentioned recommendations are supported by other studies cited in this review. Smith et al.'s⁴⁴ recommendations to address barriers identified in this category included basic PC training for emergency department staff, initiating PC timeously, that communication be addressed and that there be better documentation by outpatient professionals regarding treatment plans. De Kort-Verhoef et al.⁴⁶ recommended efforts to gain further understanding of the barriers affecting communication, while Sommerbakk et al.⁴¹ recommended education as a strategy for PC implementation, discussed in the next section.

The above studies, although in different parts of the world (Norway, Netherlands, USA, Kenya and South Africa) all suggest that challenges related to education and training are influenced by personal, interpersonal, organisational, social and economic factors. Described in different ways, it appears that education and knowledge are at the core of other factors such as motivation, awareness and confidence, belief systems and communication. The above studies therefore highlight a lack of and need for raising awareness and providing education and training in PC to service providers and service users.

2.2.3 Implementation Factors

There are many factors that could be considered as implementation factors. According to Sommerbakk et al.⁴¹ an initiative's chance of success is heavily influenced by the *resources* available in the

organisation. With an increasing number of clinical cases and administrative requirements, and with staff capacity generally remaining the same, there is little time available and motivation for change initiatives. Staffing difficulties also involve trying to include staff who were not permanent or full-time in implementing developments. With regards to structures and services, Sommerbakk et al.⁴¹ reported that limited physical space (no private room available for families to say goodbye to patients) was identified as a barrier. Furthermore, hospitals that extend over a few buildings has an impact on the success of promoting an initiative as there is less time and opportunity to engage with co-workers.

Lamba et al.⁴⁸ conducted a survey study at a large tertiary hospital in the USA to identify what factors prohibited the delivery of PC in emergency departments and discovered similar issues related to insufficient staffing and infrastructure to support PC. Responses of 30 emergency care physicians who graded 23 questions on a 5-point Likert scale were assessed. A limitation of this study was that it was department-specific and therefore potentially not relevant to all areas of a hospital. Furthermore, although the method for this study produced categorical responses, each barrier mentioned is complex, potentially requiring further analysis. The Likert scale may be able to elicit identification of general problems, but this method does not elicit a deeper understanding of these problems, nor does it allow for new information to emerge.⁴⁹ Barriers identified in this study included a lack of time for necessary communication for PC, and the emergency department setting itself not being conducive to patients in need of PC due to congestion and general commotion.

Insufficient time and infrastructure were noted again in another study conducted by Beckstrand et al.⁵⁰ in a hospital in the USA. Likert scale questionnaires were emailed to emergency care nurses to identify their perceptions of barriers related to initiating end-of-life care in emergency departments. Once again, the limitations to using the Likert scale and targeting one department in a hospital apply here. The highest-scoring barrier to providing PC care noted in this study was nurses not having enough time for patient care because of their workloads. This was followed by infrastructure of the emergency departments not being conducive to end-of-life care, and families' not realising the implications of "lifesaving" interventions. Factors that supported care initiatives were being able to allow time for the family to spend with the deceased patient, and having the deceased body prepared in a dignified way for families. Based on this study, recommendations included establishing ways to reduce nurses' workloads hence increasing their capacity to spend more time with patients and families, and - probably a more difficult task - to improve emergency care structures.

Sommerbakk et al.⁴¹ also identified the *social context of the facility* as influential in implementation of various strategies. Factors in this category related to leadership, culture of change, and face-to-face contact. Establishing a PC service in a hospital is one thing, but one also needs to consider the different departments in the hospital itself and that each department may have their own structure, set of resources, limitations and ethos. For example, studies conducted by Lamba et al.⁴⁸ and Beckstrand et al.⁵⁰ in the emergency care settings highlighted infrastructure, lack of time, congestion and chaos as barriers to implementing PC, whereas Aslakson et al.'s⁴² study conducted with ICU staff present different findings that relate more to futile interventions and care planning.

Patient factors impacting on effective implementation were identified by Sommerbakk et al.⁴¹ as non-compliance due to the burden of symptoms, and diminished cognitive function due to illness. As discussed earlier, Aslakson et al.⁴² also identified patient and family factors, including contrasting beliefs regarding treatment and dying, and different understandings of terms such as “natural death” and “futile treatment”. Cornetta et al.⁴³ identified the financial situation of families, and religious barriers as prohibiting implementation.

It is interesting to note that Sommerbakk et al.'s⁴¹ study conducted in Norway primarily mentions factors relating to the patient's physical condition (motivation, burden of symptoms, cognitive function due to illness), whereas Smith et al.⁴⁴ and Aslakson et al.'s⁴² studies conducted in the USA, and Cornetta et al.'s⁴³ study conducted in Kenya note more cultural and socio-economic factors resulting in barriers of providing P.C. This highlights how the social-economic context of the study plays a role in determining the specific personal and interpersonal factors that are identified as being relevant to the provision of PC in hospitals.

As Sommerbakk et al.⁴¹ highlight, the social context of the organisation is influenced by *leadership* and the culture of change. Leadership roles were said to be vital to the success of a PC initiative by all participants. The findings of the study emphasised that a leader should show enthusiasm regarding the initiative, ensure structures are in place (such as time allocation) to accommodate staff to be involved in the initiative, applaud staff members' contributions, and obtain on-going feedback. Hindering factors identified included a distant style of management (which caused uncertainty about patient care duties and about what change was required), and the lack of nursing representation in management. Recommendations from this study were that leaders need to encourage early participation from staff in initiatives, ensure that the staff has appropriate training in PC, and make sure that the change in the facility is consistent with the staff's ethos of care.

Linked to the role of leadership in the implementation of PC in hospitals, the role of *champions* is emphasized in most of the studies included in this review. In an article where Ntizimira et al.⁵¹ describe the progress of PC integration into the Rwandan health system, it is suggested that “through advocacy, policy and commitment to compassion, Rwandan health care workers are proving how PC can be successfully integrated into a health care system”.^{51(p1)} The importance of “champions” in the development of PC in Rwanda is highlighted. Various champions have played important roles in ensuring access to morphine and for developing services and associations that promote, support and assist in the implementation of PC.

Successful implementation of PC depends on the *implementation strategy* employed. The strategy of having a “champion” who can inspire, coach, assist and support others in the implementation process was identified as an enabler by Sommerbakk et al.⁴¹ Characteristics required of such a person include being known, being competent, and having credibility in the institution. Ensuring that the correct person is chosen as a champion was stated as essential, although it was mentioned that it is not vital to choose those most interested in PC. In fact, in one service, less interested individuals were chosen as champions as a strategic means to gain their buy-in to prevent potential obstructions.

Educational strategies identified by Sommerbakk et al.⁴¹ included the provision of PC talks and courses. However, challenges related to education strategy were linked to timing, obtaining funds and staff turnover. Facilitating factors included regularity of training, compulsory attendance, timing, and financial support. Participants in this study recommended that training be provided before big changes are implemented so that staff are prepared, and that training be offered in the evening – to avoid interference with everyday clinical practice. Employing locum staff to allow full time staff to attend training during the day was also mentioned as a facilitating factor.

Barriers to implementing strategies identified by Aslakson et.al.⁴² were related to short duration of the patient’s stay in ICU, unknown prognosis, patient’s lowered level of consciousness (impacting on autonomy), lack of advance directives and undefined family decision-makers. It is clear that Sommerbakk et al.⁴¹ refer to programme development and systemic issues, while Aslakson et al.’s⁴² findings appear to relate more to challenges regarding the patient, family and direct service offered in the ICU as barriers to implementation.

A survey study conducted by Spaulding et al.⁵² in the USA compared hospitals with PC services to those without these services to identify what environments promote the development and use of PC programmes. The study was conducted at 1132 non-federal acute-care hospitals, 518 of which had PC

programmes and 614 that did not. The study demonstrated that PC programmes that have been developed on strong evidence and based on the needs of the organisation and socio-economic context, can assist in the appropriate use of hospital resources and, in turn, can decrease financial burden. This study is significant because it highlights that programmes and policies need to be tailored, and that a successful programme in the USA, for example, may not be suitable for an African context.

Tapela et al.⁵³ in Rwanda conducted a retrospective analysis of 2326 patients' electronic medical records were completed to explore the experiences and challenges of establishing the Butaro Cancer Centre of Excellence. Tapela et al.⁵³ describe factors that prohibit PC integration as staff capacity, access to needed services such as radiotherapy, financial implications of services, and sustainability. Promoting factors related to good leadership from Rwanda's Ministry of Health that ensures the integration of initiatives into the state sector by promoting partnerships, shifting of professional roles and infrastructures.

There appears to be limited research on integration of PC services into the health care system in South Africa. Research conducted by DesRosier,¹⁰ Van Niekerk,²⁵ Hongoro,³⁵ and Ganca⁴⁷ highlighted research conducted on the needs for and benefits of hospital-based PC programmes, but they do not specifically examine factors that influenced the integration of those services. However, in their study, Gwyther et al.³⁷ report that both Victoria Hospital and Groote Schuur Hospital have produced modified PC tools and simple referral forms to address challenges related to early identification of patients in need of PC. All health care workers involved with the patient are encouraged to refer to the service and having health care workers trained in PC has assisted in identifying and referring appropriate patients. Another enabling factor mentioned by Gwyther et al.³⁷ is ensuring continuity of care by mobilising community resources. A hospital-based PC service does not start and end in the hospital. Linking with and ensuring appropriate referral to resources in the community such as home-based care is therefore considered to be vitally important. According to Gwyther et al.³⁷ partnerships between hospitals and hospices can play a role in the successful implementation of PC. For example, Stellenbosch District Hospital has an affiliation to PC in that they have partnered with Stellenbosch Hospice and have allocated ten beds for PC patients. Knysna Provincial Hospital has also formed relationships with hospices in their surrounds to get support and guidance.

Based on the review conducted by Gwyther et al.,³⁷ factors that appear to contribute to the success of the programme development are that the hospitals developed the programmes in response to real needs identified by the specific institution; they received some sort of financial assistance; and providing PC education was a strong enabling factor. Furthermore, modification and use of PC tools, staff awareness,

interdisciplinary involvement (including volunteers), government support, building partnerships, and mobilising community resources was key to success. And lastly, individual's contributions and efforts in the initiation and running of services have been identified, suggesting once again that the presence of "champions" could be one of the promoting factors in successful integration.

Although Gwyther et al.³⁷ give a clear description of the development and strengths of hospital-based PC programmes in the Western Cape, there is no mention of the specific barriers encountered in the process of developing these services. It would therefore be important to explore what obstacles were encountered and how they were (if they were) overcome, to provide recommendations for others starting hospital-based PC services.

2.2.4 Policy Factors influencing Integration of Palliative Care

The WHO PHS prioritises policy to support PC above all other components to develop the necessary health plans, funding and service delivery models, and for essential medicines.²⁹ Key factors discussed in this section include government support, policies, protocols and legislation, policy implementation and financial realities and support.

Sommerbakk et al.⁴¹ identified economic and political factors related to policy and legislation, and funding. Participants in the study reported three main prohibiting factors regarding how policies and legislation affect the organisation's ability to implement PC, namely: (1) Policies did not promote and support having a PC trained individual in facilities; (2) a lack of local champions with training in education, which was required to increase knowledge and skills of nurses; and (3) due to hiring protocols, legislation can limit the ability of services to gain knowledge and skills. For example, Norwegian legislation necessitates managers to support dismissed staff over new staff who may be better equipped to improve services. Financial assistance was also stated by all participants as crucial in the implementation of initiatives, and hence a lack of funding is a major barrier.

Another factor influencing integration of PC may be the PC implementation guidelines themselves, or how they are perceived. Kalies et al.²⁷ (2014) conducted an on-line survey in Germany and noted that health care professionals' views on PC guidelines may be a prohibiting factor in successful implementation of a PC guideline and integration of PC. This study reflected the views of 1031 multidisciplinary professionals (doctors, nurses, social workers, psychologists, spiritual carers and physiotherapists) who were members of the German Association for Palliative Medicine (DGP).

Although using a survey method limited the amount of rich data obtained, a strength of this study was in the number of professionals it was able to reach.

The most frequently reported factor by Kalies et al.²⁷ that could hinder the effective implementation of a given guideline was distrust in the quality of the guidelines. Participants were of the opinion that existing guidelines are often out-dated and many questioned the impartiality of the guideline's authors. The next most prevalent factor was reservations about guideline implementation. Participants doubted the ability to change present routines to accommodate new guidelines. Other less significant factors identified in this study were related to concerns that guidelines impact on flexibility to offer unique care, and that guidelines suggest a lack of competence on behalf of the professional. Kalies et al.²⁷ recommendations were to ensure transparency in the development of future guidelines (provide clarity); to ensure an interdisciplinary approach to development of guidelines including authors that are experts in knowledge and practice, with the goal of follow-up (instilling confidence in authors); to clarify that guidelines still allow for flexibility (staff can still provide individual patient-centred care); that guidelines need to be implemented in various stages, including presentations and training; and the use of indicators and negotiations with appropriate stakeholders.

2.2.5 Drug Availability

Although access to essential drugs was highlighted as a key component in the WHO PHS, Cornetta et al.'s⁴³ study in Kenya was the only study in this review that raised the lack of access to medication as a barrier to integrating PC. This may be because the studies selected for this review do not date back further than 2008 and that the growth in PC has made access to essential drugs for PC more possible in most countries. Although inadequate pain management was reported as a barrier in other studies, whether these factors were linked to the inaccessibility of drugs is uncertain.

2.3 RATIONALE OF THE STUDY

As outlined in Chapter one, annually, over 20 million people need PC, and the majority in developing countries. Research conducted on illnesses necessitating PC, causes of death, place of death, and the few studies conducted in hospitals to determine which patients require PC, clearly indicate the need for PC to be integrated into the health system. Patients requiring PC are often diagnosed with a life-threatening illness in hospital, and/or require hospital care at some point during the course of their illness, and/or die in hospital. Therefore, PC in hospitals is paramount to ensure patients get the care they require, and to ensure continuity of care.

There has been an increase of hospital-based PC programmes around the world, and a few programmes have been developed in South Africa, even though they have not been standardised. With various legislation and policy frameworks stating the need for and promoting the development of hospital-based PC, integration into all state hospitals in South Africa will be a requirement. Although this has been stipulated as the way forward, little research has been done on “how” to integrate services into a state hospital setting, and even less so in South Africa.

Policy is required to ensure adequate resources to integrate PC into the health system including hospitals, but how one implements legislation that requires resources, in a resource scarce society, is a major challenge. Research has clearly shown that there is a need; the need has generated planning; and various policies have been produced. The next step is to address the numerous implementation challenges noted in this review. This serves as a foundation for this study on the factors that influence integration of PC in a hospital.

2.4 STUDY AIM

This study’s aim was to investigate factors that influence integration of PC in three state hospitals and, based on the findings, to develop implementation recommendations.

2.5 STUDY OBJECTIVES

The study objectives were:

- (1) To describe existing PC services in three state hospitals in the Western Cape as perceived by the PC team;
- (2) To identify prohibiting and promoting factors in the integration of PC services in the three hospitals; and
- (3) To elicit views on how challenges to integrating PC in a hospital setting could be addressed.

2.6 CONCLUSION

All the selected studies were published between 2008 and 2017 and were conducted within health care facilities, mostly hospitals. Most of the studies were based in the USA and Europe, suggesting the need for further research to be conducted within the African context and especially within South Africa.

Most of the studies’ aims were to explore views of health care professionals on barriers and/or enablers of integrating PC and made use of interviews and/or focus groups to obtain data which appeared to be

rich and appropriate in terms of the study aims. Some of the interviews used surveys which then reached a larger proportion of participants. Two of the studies used Likert scales which may have been limiting in obtaining rich data and identifying factors not yet known.

Various prohibiting and promoting factors influencing integration of PC in the facilities were identified and presented within the WHO PHS framework. Some of these factors overlapped and some were also a result of one another. Human resource challenges were identified as a barrier in almost all reviewed studies. Lack of material resources was identified as the next major barrier followed by patient and family factors, lack of PC awareness, knowledge and skills and factors relating to leadership and governance.

In conclusion, of the international and national studies reviewed, facilities – whether hospitals, nursing care homes or other health care facilities – appear to have experienced similar challenges and recommend similar strategies for successful implementation of PC services. In most cases, promoting factors in integrating PC services include the ‘other side of the coin’ of the prohibiting factors mentioned above and vice versa. Most of the studies identify barriers at various levels, namely health care provider, patient, organisational, and policy factors, suggesting that addressing barriers requires a comprehensive approach that includes all levels of the system: micro, mezzo and macro levels.

CHAPTER 3: METHODOLOGY

3.1 INTRODUCTION

In chapter three, the research methodology⁵⁴ is described; how the researcher went about to address the research question: “What factors influence integration of PC in state hospitals?”.

3.2 STUDY DESIGN

This was a qualitative study that required the researcher to “collect data in the form of written or spoken language, or in the form of observations that are recorded in language, and analyse the data by identifying and categorizing themes.”^{55(p47)} An explorative and descriptive design was used as thoughts, feelings, perceptions, and behaviours were explored and identified in order to answer the research question.⁵⁵ A qualitative approach was chosen for this study because a small sample was used, and because the phenomena under investigation were relatively unknown and hence the methodological guidelines more flexible to cater for unknown truths to emerge. The nature of this study required an explanation of in-depth perceptions and views on the particular topic to be elicited, which may be restricted if conducted within a quantitative approach.⁵⁴

3.3 STUDY SITE

The study sites comprised three State hospitals (2 district, 1 tertiary) that currently provide PC services in the Western Cape. All facilities serve large catchment areas catering primarily to low-income populations. The hospitals involved in this study were identified from experts in the field who have the knowledge of the PC services offered in these settings.

3.4 STUDY POPULATION

The population, which refers to all probable participants in the study,⁵⁶ comprised health care professionals and management considered to be key informants⁵⁵ working in specified health care facilities that provide PC services.

3.5 SELECTION CRITERIA

The following inclusion criteria guided the choice of research participants in this study: Hospital management personnel including chief executive officers (CEOs), nursing managers, and clinical managers); PC programme directors or managers; and multidisciplinary team members involved in the PC programme (doctors, nurses, social workers, and pharmacists). Participants were considered based

on their experience/knowledge of PC in their organisation, holding either a clinical or administrative role in the PC team, or in a hospital management position where knowledge of the organisational structure was presumed. Exclusion criteria were hospital staff members who are not involved in the PC services in the relevant facility.

3.6 SAMPLING

Purposive sampling⁵⁷ was used for this study. Focus was on selecting research participants who had specific characteristics required for the study: those who have experience, knowledge and/or skills in the implementation of PC services in their institutions.⁵⁵ At each of the three hospitals, five-seven key-informants were identified. Depending on the staff structure and PC team composition in each hospital, key informants included chief executive officers, nursing managers, PC programme managers, physicians, nursing sisters, pharmacists, social workers, and in one case, a hospice nurse involved in the hospital programme.

3.7 RECRUITMENT OF PARTICIPANTS

Recruitment started after the study had received ethics approval from the University of Cape Town's (UCT) Human Research Ethics Committee (HREC) (Appendix A), and permission to conduct the study had been obtained from the Department of Health to conduct research at the three hospitals concerned.

The researcher emailed and telephonically contacted the CEOs of the three hospitals to introduce herself and inform them of the study. Relevant key informants' contact details were obtained from the PC staff of the UCT School of Public Health & Family Medicine, and other contacts that the researcher has from her experience in the field.

Telephonic and email contact was initiated with the relevant key informants involved in the PC programmes at each hospital to introduce study and request participation. Names and contact details of other relevant key informants were obtained (snowballing).⁵⁵ All participants received an email with information about the study and a consent form (Appendix B), and a letter of approval to conduct research at their facility.

Once participants had agreed to take part in the study, the researcher, via email or telephone, arranged an interview date and time with the participant at his/her office or another private venue most convenient to him/her. The interviews were scheduled in working hours and lasted approximately 30-60 minutes.

Prior to the start of each interview, an informed consent form (Appendix B) was provided, reminding the participant of the research project's aims and objectives. The researcher allowed time for the participants to read through the information and offered to answer questions or clarify anything that may have been unclear. In line with ethical principles, participants were informed that refusal to take part would not compromise their position in their organisation or their professional reputation. Participants were assured anonymity and confidentiality, and the researcher made it clear to the participant that his/her participation was voluntary and that s/he may withdraw his/her participation at any time. This meant that any presentations of their views, including published reports, would be anonymous (unless otherwise requested by participants), and that the data emerging from the study would be stored safely and securely in a locked cabinet in the researcher's work office. Once participants were happy with the information provided and had the opportunity to ask questions, consent forms were signed by both the participant and the researcher and witnessed by staff members not involved in the study.

3.8 DATA COLLECTION TOOLS

The interview questions were guided by a semi-structured interview schedule (Appendix C) which related directly to the research aims and objectives of this study.⁵⁷ The interview schedule was developed through a discussion with various key informants in the field of PC which included the Director of Hospice Palliative Care Association, a social worker lecturing in PC at the University of Cape Town (UCT), and a strategic development consultant for Hospice Palliative Care Association. To elicit thick descriptive information, the questions were sufficiently open-ended to allow for the subjective view of participants to be conveyed yet guided the participants to describe their services, their views on the prohibiting and promoting factors in the development and provision of services, and to give their recommendations on how PC could be integrated into other state hospitals.

To ensure that the interview tool was considered trustworthy⁵⁸ the researcher conducted an appropriate and rigorous literature review, and developed a valid data collection instrument, checking the instrument with experts in the field before use in the main study. The researcher piloted the tool by identifying two willing participants who understood the context yet did not form part of the study. As a result of this pilot, minor editorial changes were made to the interview schedule to ensure clarity of the questions.

3.9 DATA COLLECTION PROCESS

The method of data collection used to obtain information in this study comprised 17 semi-structured, in-depth one-on-one, face-to-face interviews. Besides asking the questions during the interview, exploring,

clarifying, and summarising skills were used to reflect understanding, and to ensure information provided by participants was perceived correctly.

The researcher conducted the interviews in English, at the participants' place of work, at a convenient time for them. The verbal content of the interviews was recorded using two audio recorders. Informal notes were taken during and after each interview which were useful to refer to when prompting further information. Formal field notes were not included as a data source in this study.

3.10 DATA ANALYSIS

This study was guided by an inductive approach which reflects an interest in the development of new theories from information gathered.⁵⁵ The recorded interviews were transcribed verbatim by an independent professional, checked and analysed by the researcher, using the steps of thematic analysis.⁵⁵ ⁵⁹ Using hard copies of the transcribed interviews, the researcher read and re-read the material to be familiarised and immersed in the data, gain critical understanding of the content and identify emerging themes and subthemes.⁵⁵ No computer-assisted software was used to analyse the data.

Following Creswell's steps of data analysis,⁵⁹ the researcher began by reading through all transcriptions to get an overall sense of the data, followed by critically examining each interview, searching for any hidden or underlying meaning in the data while making notes and highlighting relevant sections using coloured highlighters. Various topics were identified, abbreviated, coded and recoded, and grouped into categories, and then reviewed again, resulting in the emergence of themes and subthemes. Data that did not have a place in any specific category were then recoded and placed into a relevant or new category. The researcher compiled and maintained an electronic table where the information was collated for easy viewing and organising. This method gave the researcher an opportunity to look at the data at different phases, as well as add, omit, collapse or extend themes accordingly. A summary of the findings is outlined in Appendix D.

3.11 STRATEGIES TO ENSURE ANALYTICAL RIGOUR AND TRUSTWORTHINESS

An important measure of good qualitative research originates in the idea of trustworthiness, which promotes objectivity of the research findings. For research to be considered trustworthy, it needs to be credible, transferable, dependable, confirmable and reflexive.⁵⁸

Credibility asks the question: "is this true?". This reflects an attempt to stay true to the constructed reality expressed by the participants, rather than the interpretation of views expressed from the interviewer's own framing of reality. Strategies to ensure transferability (the degree to which the findings of this

research could be useful or relevant to other contexts or with other participants) were through key informant sampling and eliciting thick description while collecting data.⁵⁸ Dependability refers to the extent at which the findings are repeatable.⁴⁰ The rigour of the research process pursued in this study reflected the researcher's attempt to enhance the dependability of the research process and the findings.

Conformability relates to the genuineness of the findings; the true findings versus the bias of the researcher.⁵⁸ As this was a qualitative study, it was important to clarify the researcher's own investment in the research and to consider herself in this context. Reflexivity requires that one is aware of one's own interests, particularly within the context of power relations.⁶⁰ The researcher's current role in PC in a hospital setting potentially strengthened her role as a researcher in the field. However, there was also potential of bias given that she has her own view of what factors influence integration of PC in a state hospital. The researcher strived to remain self-aware and objective in the interviewing process by ensuring that the questions in the interview schedule were not leading, were the same for all participants, and that her interviewing skills facilitated an objective process whereby the participant felt free enough to voice his/her own views.

3.12 DATA STORAGE AND CONFIDENTIALITY

Steps to ensure confidentiality included ensuring that the views expressed by the participants in the three hospitals would not be linked to specific names or institutions. The data is therefore stored in a locked fire-proof cabinet in the Social Work Department at Victoria Hospital. Only the researcher has access to the key for these cabinets. Computers and mobiles where data were stored was password protected and only the researcher has access to these passwords.

3.13 ETHICAL CONSIDERATIONS

Ethical procedures were followed to protect the research participants.⁶⁰ The study commenced only once approval was obtained from the UCT HREC, and permission received from Department of Health, and Facility managers. The study posed no risks to the participants. The researcher ensured that the benefits of the research outweighed any potential harm and that autonomy of the participants was upheld. The following ethical principles were pursued: Confidentiality, privacy, voluntary participation, anonymity, transparency and informed consent.⁶¹ To ensure confidentiality, fictitious names, letters or numbers were used in the coding process. Audio recordings and hard copies of the transcriptions and informed consent forms were kept in a locked cabinet in the researcher's office and only accessible by the researcher. This

data will be retained for a minimum period of five years as stipulated in the Medical Research Council Guidelines on the Responsible Conduct of Research.⁶²

3.14 CONCLUSION

Chapter three described the research methodology used for this study. This was a qualitative study whereby individual semi-structured interviews were conducted with 17 key informants (five-seven at each hospital). To obtain perspectives from those on an operational and management level, key informants included chief executive officers, nursing managers, PC programme managers, physicians, nursing sisters, pharmacists, and social workers. The data was recorded, transcribed and analysed through steps of thematic analysis. In the following chapter the results from this analysis will be presented.

CHAPTER 4: RESULTS

4.1 INTRODUCTION

In this chapter the researcher will present results collated from data collected from one-on-one semi-structured interviews conducted in a qualitative study to determine factors that influence integration of PC in a state hospital. The data was analysed, coded and grouped into themes and subthemes which are presented in a table below (Table 1) and elaborated on thereafter.

4.2 SAMPLE DEMOGRAPHICS

A total of 17 key informants were invited to and accepted participation in the interviews, of which nine were female and eight male. Of the participants, a social worker, nurse, doctor and CEO were interviewed at each hospital to ensure that information was gathered at an operational and management level. In total, one pharmacist, three social workers, four nurses, five doctors and four staff in management were interviewed. Only three nurses had formal PC training, while the other participants had exposure to and/or experience in PC.

Table 1: Characteristics of Key Informants

Key Informants		Number
Sex	Males	8
	Females	9
Profession / Occupation	Nursing Sisters	4
	Social Workers	3
	Physicians	5
	Nursing Management	1
	Chief Executive Officers	3
	Pharmacists	1
PC Role	Employed to treat PC patients only	4
	Employed to treat all patients including PC patients	9
	No direct contact with patients – management role only	4

4.3 DESCRIPTION OF PALLIATIVE CARE SERVICES IN THREE STATE HOSPITALS

Details of programme development, infrastructure, PC teams, programme coordinators, PC qualifications and experience, funding and in- and out-patient PC services of the three hospitals are presented in detail in Table 2.

Table 2: Description of Palliative Care Services in Three State Hospitals

	Hospital 1	Hospital 2	Hospital 3
Reason for development	Medical intern's experience of a 27-year-old patient die of kidney failure in the hospital	Research showed the need for PC	The need to reduce costs by improving the support for "frequent flyers" – revolving door patients & Training offered by NGO
Infrastructure	No PC beds Service integrated into normal hospital system	PC is integrated, besides a ward with two beds dedicated to PC patients for privacy etc. Dedicated family room Office space for core PC team	PC is integrated into hospital – then an intermediate care facility for hospital patients only
Funding	Majority of PC team hospital staff (only one dedicated to PC only) – stipends for other team members paid by hospital board	Currently hospital supported. First PC position (nursing post) was funded by an NGO for one year before it was funded by hospital.	Hospital and conditional grant
PC Team	Medical consultant Professional nurse Volunteers: 2 X bedside counsellors 1 X administrative clerk Patient Family members Dietician Physiotherapist Occupational therapist Coordinator - Professional nurse Nurse-driven, doctor supported	2 nurses (1 is the coordinator) 2 auxiliary social workers (supported and supervised by social worker HOD) Doctor from UCT (honorary basis) does ward rounds and consults OT (Hospital staff) Physiotherapist (Hospital staff) Speech therapist (Hospital staff) Postural care (nun paid by the church) – don't pay for religious services, they are allocated but not based here Coordinator professional nurse Nurse-driven, doctor supported	Multidisciplinary team that includes disciplines from hospital and Hospice On-site Doctor (Hospital but has some PC training) Pharmacist head Social worker that never comes Nurses that seldom attend meetings / ward rounds Hospice doctor Hospice Nurse Hospice Social worker Volunteer counsellor and pastor OT mentioned by one Physiotherapist Hospice nurse and SW sometimes join Coordinator Hospice nurse / hospital doctor
In-Patient Services	First assessments using assessment tool Advocacy for quality care in wards Counselling & support to patients & families Bedside counselling and care Facilitation of palliative / respite care placement Interdisciplinary team PC meetings (weekly) PC ward rounds (weekly)	Everyone in team that is relevant to specific case sees patient Only in-patient Assessments Family meetings Breaking bad news Educating families Ward rounds Discharge planning Care planning Referral to step down	In-patient services Referrals from ward rounds Academic ward rounds twice a week (hospice joins) Hospital doctor does ward round a few times per week at intermediate care facility
Out-Patient Services	Home visits by registered nurse Telephonic follow-ups by volunteer Patient and family / carer support group (every second Saturday) Charity shop	Follow-up call within 72 hours of discharge WhatsApp	None offered directly by hospital staff, however hospice provides services at home

4.4 EMERGING THEMES AND SUBTHEMES

Main themes were guided by the research objectives while sub-themes emerged from the analysis of the data.

Table 3: Themes and Sub-themes

THEME ONE	THEME TWO	THEME THREE
Enabling factors for integrating PC	Prohibiting factors for integrating PC	Recommendation for integrating PC
2.1 Staff awareness of PC needs and benefits	3.1 Hospital culture	4.1 Acknowledgement of the need for raising awareness of PC
2.2 Staffing for PC	3.2 Resource challenges	4.2 Programme development
2.3 Material and financial resources for PC	3.3 General training challenges	4.3 Adequate resources
2.4 Education and training in PC	3.4 Health care provider challenges	4.4 Education and training in PC
2.5 Support structures	3.5 Patient, family and community factors	4.5 Networking and building partnerships
2.6 Partnerships and community-based support	3.6 Policy factors	4.6 Policy recommendations

4.5 THEME ONE: ENABLING FACTORS FOR INTEGRATING PALLIATIVE CARE

Five subthemes linked to enabling factors were identified, namely: Awareness of PC needs and benefits; resources, education and training in PC; support structures; and partnerships and community-based support.

4.5.1 Staff Awareness of PC needs and benefits

Most participants in each hospital mentioned that PC saves money and prevents unnecessary interventions by reducing the number of readmissions thus preventing people from dying in hospital.

“Financially people are realising that we’re spending massive amounts of money all over the world on the last six months of a patient’s life” P4

“the aim of this type of care would be to reduce the number of readmissions to the hospital” P5

Having a hospital culture conducive to PC was considered an enabler.

“[Name of hospital] in itself has got a very different vibe that’s got a very distinctive hospital culture, and that culture of [Name of hospital] has been very enabling” P3

A few participants stated that for PC to really work, this service needs to be viewed as a continuation of care rather than a separate service.

“It’s always nice to be able to be part of a chain which is completed in essence rather than just being able to provide what we can provide and then throwing patients back out into uncertain care” P11

Many participants reported the value in using practical methods of raising PC awareness. The most commonly referred to method was conducting research and obtaining statistics, followed by using stickers to identify PC patients and exposing staff to PC.

“in terms of getting over the challenges of getting the buy-in of management, research is key. When you can prove through your work that you can show evidence that you are achieving better outcomes, cost saving, and improving quality of care, then it’s hard to actually challenge that” P3

“the need for the emergency unit to actually understand palliative care, meant we were identifying patients by means of putting a special sticker on their folder, and initially, when they saw the sticker, they had a sense of at least this patient has got a plan” P3

4.5.2 Human Resources and Teamwork

All participants mentioned enabling factors linked to human resources. Many participants reported that the existence and success of their PC programmes has been mainly due to the presence of PC champions and referred to characteristics of PC champions as being the driving force for successfully developing PC in the hospitals.

Passion as a fundamental characteristic was mentioned by a large number of participants, followed by advocacy.

“This sort of just survived, and I think through passion and the will of the people that were involved, it continued” P4

“You need to have a passion for patient advocacy. You need to know that you’re going to get into trouble with certain people, and butt heads and come up against the establishment” P2

Resilience was reported as another fundamental characteristic of a PC champion by a few participants.

“whoever actually becomes a champion for PC has got to have a thick skin, or if they don’t have a thick skin, they’ll develop one rapidly” P3

“you need all the characteristics that someone starting a business would have. Grit, determination, resilience, because it’s really difficult to get something like this off the ground” P4

Another characteristic which was mentioned by a few participants was having had a personal journey with loss, witnessing the impact of loss in their work environment, and/or losing someone close to them.

“I think experiencing loss and having those kinds of challenges has developed them as people and has made them want to continue this kind of work” P2

Staff involvement was reported as an enabling factor by many participants. Various disciplines or professions were referred to in this regard. Some participants stated that having social workers, social auxiliary workers involved in their PC programme has been a promoting factor.

“I think they have just naturally taken to it. Many of the patients’ problems are social actually, and many of their issues around dying are also social” P7

“I’m trying to keep building on this service with auxiliary social workers because I think it’s working out quite well. It’s not as costly as appointing a registered nurse, and you know, they have a softer approach to the patient, being in social work” P17

A few participants stated that having volunteers assisted in developing and providing PC services. One participant described her experience with a highly qualified individual who volunteered her expertise.

“I did find that I got a lot of help when I had a second professional coming into the organisation” P2

Having the support of a doctor, a nurse or a clerk for PC were also each reported to be a great help as well as having a large junior component of clinical staff which one participant explained keeps the permanent employees up-to-date with needed knowledge.

“There was a reason why we set this up for a larger clinical component. We set it up so that it kept us on our toes to revisit a lot of our protocols and we had to orientate and explain to team a lot” P10

Effective teamwork which entailed working towards a common goal was identified as a promoting factor for PC by many participants. In line with this, having a multidisciplinary approach and effective communication was important for effective teamwork.

“We’re all working towards one goal – and that is towards what is in the best interests of the patient and the families” P1

“What makes this system strong is that multidisciplinary approach because it seems to me, that one cannot really do without the other” P12

“ongoing continued open channels of communication between all role players” P11

4.5.3 Material and Financial Resources for Palliative Care

Having enough infrastructure and material resources was considered important for providing adequate PC by several participants. Having a private room and PC beds was considered an enabler to respecting the patients’ and families’ needs for privacy, as well as limiting other patient’s exposure to death.

“they were going to die in hospital so instead of dying in the emergency unit they moved them to another area and that has been very helpful” P8

One participant explained how having designated office space for PC has provided the team with a sense of identity.

“They have got a nice space now and they have got some offices and we worked to give them somewhere to sit and all of those things and they have an identity” P7

Having an intermediate care facility on the hospital site was also considered to be a promoting factor in the provision of PC by a few participants.

“We have a palliative care ward on our premises. So, if you discharge a patient who you are not completely able to send back home, at least you have the cover or the support” P16

Financial support was reported as an enabler by a few participants. One participant explained that funding was vital for development of the PC programme. Accessing financial support and assistance from hospital management, board and academic funds was also considered important.

“You asked me, how do you start a palliative care service, you have to have money. There is no question in my mind and without that it would never have happened” P7

“Where I think we have supported is through fundraising and the hospital has done, the management team, partnering with the board has done quite a bit of fundraising” P4

A couple of participants highlighted the value of conditional grants offered by the Department of Health.

“I must also complement our district office, the Department of Health higher up, they have good projects with conditional grant components also making funding available for relationships with NGOs” P10

One participant stated how donations have helped.

‘people are reaching into their pockets and offering what they can to make this a success and I think therein lies the benefit of setting up relationships and having people understand this is important to us and by hook or crook we are going to make this a success’ P10

4.5.4 Education and Training in PC

Formal training for staff was reported as an enabling factor by many participants. When asked what the biggest help was in creating awareness and getting buy-in, one participant confidently answered:

“training, training, training!” P6

Other participants expressed the importance of training by reporting the following:

“It does improve all spheres of care, and it’s not just a certain part” P10

“Many of the sisters have now had some basic training in palliative care which at least has increased awareness along the way” P7

Training provided by certain PC specialised organisations such as Hospice Palliative Care Association and Hospice was reported by some participants as a major help in training staff.

“they trained quite a few people like nursing staff, social workers and they did a few dieticians....so that has been very helpful because it has made us aware of the need” P8

The hospital being a training facility for Family Medicine was also identified as a strength by a few participants.

“We’ve got a family medicine programme here so part of their course is palliative care which definitely helps so you can easily develop champions for palliative care primary health care and champions for palliative care in the hospital” P15

Management supporting formal PC training by freeing up staff for training was helpful.

“we would set up training sessions and make sure we freed up our staff, I think that is how over time we chipped away at the challenge” P10

Attending conferences and symposiums were reported to be useful methods of obtaining education in PC by a few participants. When referring to a colleague, one participant said:

“she came to the HPCA conference last year and we came away with a host of ideas” P13

Another participant stated:

“after that I felt so inspired and you feel like there’s so much to do” P16

A further participant commended a colleague on his search for learning opportunities.

“he will always go and find out more knowledge for himself...he will attend conferences and go and learn from other countries and come back with that, their experiences and their knowledge, and see how we can implement it into this hospital” P1

Informal training of staff in the form of academic ward rounds and PC teams talking to new rotations of doctors every three months has aided in increasing levels of PC education in the hospital.

“It’s sort of a teaching ward round, where we teach” P6

“when there is a change of rotation so like in medicine or surgery, or when there is new registrars or new interns, they allow us to come in as a team to talk to the new staff to say this is our programme” P8

A couple of participants reported that information sessions in the community have assisted with educating patients and families about PC.

“we started training the patients better, so if they go to hospital, this is what they need to talk about” P13

4.5.5 Support Structures

A few participants mentioned that having coping mechanisms has enabled them to maintain the strength to be a part of the development of PC. Self-care, working on one’s own personal growth and having boundaries were mentioned. Family support was also reported, as well as taking medication for anxiety.

“My support system and structures at home are in place and then also looking after myself” P9

One participant highlighted the need to have support built into the job for those working in PC and having the supportive function as part of the job description.

“I do think people underestimate how difficult it is to be working in a palliative care setting...and if you don’t actually have support built in for them, then they will burn out...part of my job that was built in, as my job description was to support the service” P6

Therapeutic support and debriefing was also noted as an enabling factor, with a few participants referring to the value of the employee wellness programme (ICAS).

“The passion needs to be supported and therein lies a lot of debriefing” P10

“Some of the staff members have identified unique personal challenges. They needed support which then we have set them up directly up with ICAS and we also have had group sessions with them” P10

Management supporting PC was reported as an enabler by many participants. Participants that hold management positions highlighted management buy-in and support as being one of the reasons for the success of the PC programme.

“There was definitely management support that sort of fanned the flames” P4

“the management team was instrumental in, and quite progressive making sure that we don’t externalise the service” P10

Some participants who experienced support from management expressed the following:

“We’ve got senior management supporting us, we’ve got the head matron supporting us very strongly, so all those factors have made a huge difference” P6

“There was support from the CEO of the hospital who understood the need” P7

A few participants reported that good communication channels aid in the provision of PC. Access to meetings, PC on the meeting agendas, reporting structures and open-door policy to management was considered important.

“they gave me management support where I can give input into the meetings and go to the meetings and if I have challenges, I can speak about it in that meeting” P9

Enabling policy was considered as promoting a supportive environment to providing PC. Government interest and commitment to PC was identified as an enabler by a few participants.

“I think the last thing that’s giving it some push now, came fairly late, is the interest of national government in palliative care and the recognition by senior manager in the department” P4

One participant reported that having the National Policy has been an enabler.

“I think the national policy has helped, the fact that there is a policy that says palliative care must be there” P6

4.5.6 Partnerships and Community-Based Support

Many participants reported that networking and partnerships helped in the development and provision of PC in the hospital.

“It’s access to organisations, its access to networks of people, it’s also access to policy makers and things like that, that all assists” P6

“we have got very good relationships with the hospices, the home-based care people, the placement institutes like (name of two intermediate care facilities)... We’ve taken the trouble to get to know them and to actually find out what these places are like” P2

Many participants reported that support from other organisations was a huge enabler. Home Based Care, HPCA and Hospice were reported to be organisations that supported the development of PC in the hospitals, however Hospice was referred to most frequently.

“I definitely think the good relationship we have with Hospice, that we can phone them at any time for advice and they will give you advice, or if you need a syringe driver or something, you can phone them any time” P16

Support from patients, families and the community were reported as an enabling factor by a few participants. One participant explains how community buy-in and support assisted in the development of services.

“The buy-in from the community has been unbelievable. From the first year we started the service, the community had an old family member, an old aunt that was in the program and they were so appreciative of the service, that the community actually started mobilising themselves to raise funds for us” P3

Patient and family feedback (compliments and complaints) was also identified as an enabling factor.

“whenever we wanted to quit, the patients and their families who say thank you and when you see benefits for them, you realise what we’re doing is the right thing” P3

“Another big enabler are complaints. So, there’s been a lot of complaints, so as soon as complaints come through, and it’s obviously just because there was no palliative care, it’s a big enabler to jump on board of the complaints” P6

4.6 THEME TWO: PROHIBITING FACTORS FOR INTEGRATING PALLIATIVE CARE

Six subthemes linked to prohibiting factors were identified, namely: Hospital culture; resource challenges; education and training challenges; challenges relating to health care providers; patient, family and community factors; and policy factors.

4.6.1 Hospital Culture that Prohibits PC Integration

Certain attitudes and beliefs about PC were mentioned as a prohibiting factor by some participants. A few participants reported that PC is not viewed as important as other services.

“The difficulty with palliative care is it’s not sexy. Doing a heart transplant, you’re considered to be amazing. But if you do a palliative care consult, you’re just, nobody notices because the outcome of a transplant is life. The outcome of a good palliative care service is a good end of life” P3

“I think if we’re really going to be honest and you told me you have to shut down orthopaedic surgery or palliative care, I would say palliative care. It’s not a really nice thing to say, but I have to be honest about the answers. So, it’s not fully valued as an equal partner” P4

A few participants stated the difficulty in developing services because PC is so often seen as someone else’s problem.

“I think it’s the attitude that palliative care is someone else’s, it’s a special programme, not an integrated programme” P4

“People tend to say you are the palliative care team, so you deal with the patient” P8

A few participants referred to the difficulty that people have with change.

“It’s a change, if it’s something new then it’s always difficult” P7

Some participants raised the challenge of providing continuity of care. One participant referred to the lack of continuity of care within the hospital while other participants referred to the broader health care system.

“Another challenge is the continuity of care...you can have five or ten doctors treating one patient and everybody tells a different story, so I think continuity of care is a big challenge” P16

“As soon as they leave the hospital, we kind of lose touch and the palliative care sister can’t follow up on every patient. So, I tried setting up a link with the home-based carers, but you know, there is just too many layers in between” P17

A couple participants stated that the pressure for bed turn-over in the hospital impacts on the ability to provide adequate PC as well as the belief that a PC patient is merely taking up a bed and cannot be helped.

“They stay in the ward, which is also not ideal, and then we get severe bed pressure and you stuck with someone who you can’t help” P15

4.6.2 Resource Challenges

Staffing challenges were identified as a prohibiting factor by almost all participants. Insufficient time for PC appeared to be one of the biggest barriers for PC development. Two participants reported that a lack of time is not unique to PC but is a general challenge in clinical services.

“I think a huge barrier in the public service is time...I think the pressure of the actual clinical service as it is happening currently, it is so overwhelmed that it is very hard to find space for something new...It’s not unique to palliative care” P7

Other participants confirmed that lack of time is a barrier in the health care system but added that PC cases require more time than other cases because of the difficult conversations it often requires, and because of symptom management.

“in the public health care system, we are already rushed for time. And then you’ve got to spend an extra ten to twenty minutes having a conversation that’s very difficult in the middle of a twenty to thirty patient ward round” P3

Staffing in the hospital in general (not specifically related to PC) was reported as an issue by several participants.

“I think the main barrier to this programme continuing is staffing. If we don’t get enough staffing, we are just going to stagnate, and I think the people working here are going to get burnt out” P8

Many participants reported a lack of staff dedicated to PC. Challenges regarding having enough nurses for PC was mentioned by some participants.

“I was the only sister doing palliative care so there was no leave replacement, so when I come back, I come back to all that work I left behind” P9

Two participants believed that the reason for a lack of nurses for PC was because of nursing management’s resistance to make specialist posts.

“There are lots of vacancies and so it is possible to appoint someone...They are very resistant because they want general nurses that they can move around, and they don’t want specialist nurses” P7

A few participants stated that not having social workers and doctors dedicated to PC has been a barrier in providing adequate PC.

“a social worker plays a vital role which our palliative program doesn’t have at the moment” P1

One participant reported that the sustainability of a PC programme is diminished if the programme relies on individuals.

“if I didn’t say I was going to be at the meeting, then the meeting wouldn’t happen or if I didn’t send out a reminder that it was time for the meeting again, and it was every other week, they wouldn’t come” P13

A few participants referred to PC as emotionally taxing work that requires a lot of, and constant energy, that can lead to burnout.

“there is so much that is taxing on the mental health also of our staff and the patient team” P10

Some participants reported that rotating staff, and untrained students and volunteers posed a challenge for implementing PC because of the additional energy and time required for training and mentoring.

“there are very few permanent people, so every six months you start the story all over again. So especially, people coming from other universities, or from other countries, who have not had any palliative care exposure” P6

“I’m working with volunteers who are not trained as in the medical field... a lot of the volunteers tend to still need a lot of nurturing of their own” P2

A lack of infrastructure and material resources for PC was reported by many participants. Several participants referred to a lack of resources in the community, such as care facilities and care aids, and patients’ homes not being conducive to care.

“the other barrier to successful palliative care is resources; resources in the community” P8

“we need more access to palliative care facilities” P15

Limited private areas in the hospital for health care providers to have conversations with families, as well as for patients to die, was reported by a few participants.

“I had to counsel families in the aisles and in the wards and in treatment rooms where it is so dirty and untidy and that is not how you treat people” P9

“we need better single private areas for patients to die. Not just for that patient and their family, but also for other patients...it’s terrible when the patient who is lying next to you dies” P3

Limited or no access to appropriate medication for PC was reported to be a barrier by one participant.

“we don’t always have the drugs that ensure advanced palliative care” P6

Lack of funding for PC was reported by many participants. A few participants reported that economic challenges and budget reductions have prohibited the growth of their PC programmes.

*“I think finances has been a big problem. As much as they have enabled us, there was very strict instructions of the cost ratio, the cost factor. So, I feel like we need three more sisters and a full-time social worker, but I’m never going to get that” P8*A few other participants stated quite adamantly that there are funds, but they are being spent on unnecessary interventions and are not being appropriately shifted to support PC.

“I have a very big problem with the way we are practicing health care at the moment. We are spending money on things that we can’t fix and it’s actually ludicrous how much money is wasted” P15

“just be clear, the finances are available already, you don’t need new finances, you just need to decide instead of spending so much million on oncology treatment, you going to take a little chunk of that and actually stop and spend it on palliative care” P7

One participant identified fundraising as a challenge.

“the challenge of when you start up this programme, who is going to assist in fundraising, because the reality is, is that you’d like there to be no cost” P3

Lack of emotional support was a theme highlighted by a few participants. One participant stated that the emotional support that the PC staff require is not available.

“If you don’t actually have support built in for them, then they will burn out and that is not there yet” P6

A few participants stated how a lack of management support prohibited the development of PC services: the lack of visibility of management, management not wanting to make PC nursing post full time, and lack of recognition and growth opportunities for nurses in PC posts. One participant explains how she feels her growth is unsupported.

“we have been put in this post and people forget about us, you see because I am not a coordinator...So the challenge now is will they promote me” P9

4.6.3 General Training Challenges

Lack of PC training was stated broadly by several participants.

“many of these people have not been trained in palliative care” P6

“So definitely we need more training in palliative care” P16

Linked to a lack of training was lack of time and funds for PC training. Some of these participants reported that there is limited or no time for training.

“I just haven’t had a chance to go yet...sometimes the work demands are just such that you can’t, and sometimes the training runs over a couple of sessions over a few weeks and to get to all of them is impossible, so we just land up not going” P11

“it becomes very difficult because now it affects our operational requirements” P12

One participant referred to the training costs as a barrier.

“I was always told that if you take a nurse out of her position and send her for a three-hour training, that’s costly, because who is going to work in her place?” P3

A couple of participants reported that some people are not interested in PC, even if they had the opportunity, and, some that have the opportunity, do not always implement it.

“We have training sessions but those in attendance would look at the invitations and say that’s not my field of interest” P10

“We have trained many people and not everybody has been motivated to implement palliative care” P13

4.6.4 Challenges Relating to Health care Providers

Many participants reported challenges relating to doctors. Participants reported that doctors are not providing comprehensive care in line with PC principles including inadequate pain management.

“they assess the problem and don’t always assess the whole person” P13

“they stopped all the pain meds because none of the patients had pain and I said, do you think they have no pain because they got their pain meds routinely? And if they didn’t get their pain meds routinely, maybe they would have pain? And, oh, I haven’t thought about that” P13

Another participant argued that doctors believe that PC cannot be practiced alongside curative interventions.

“People don’t understand palliative care, that the oncologists for example think there are no palliative care patients in oncology which is nonsense and that they decided that palliative care only comes at a point rather than alongside” P8

A few participants mentioned that the tendency for doctors to over-focus on curative interventions and pursue treatment that will no longer benefit the patient constitutes a barrier to PC.

“It’s the challenge of getting doctors to understand that they can’t save every patient” P3

“we focus too much on initially the diagnosis and what is wrong with this patient, and what tests must we do and send for CTs and scans and whatever, and we neglect the fact that, what about the patient and what about their family and do they even understand what is going on, and do they want this treatment” P16

Hierarchy between doctors was identified as a prohibiting factor by one participant.

“In medicine, there’s always this hierarchy, so a professor doesn’t listen to an intern necessarily. And the intern is going to find it very hard to teach the professor new tricks” P3

Doctors’ inability to communicate effectively was reported by a few participants; mainly in relation to having difficult conversations and having family meetings.

“It’s easier to avoid those conversations and the time it takes, and people are busy, and they don’t want to have those discussions” P7

“The most obvious glaring deficiency in the training of doctors in their inability to have family meetings” P3

A couple of participants explained that the reason for doctors’ poor communication could be due to their fear of death, language barriers, as well as a lack of empathy.

“I think the doctors in this hospital, many of them, completely avoid thinking about death...and sometimes you don’t even speak the same language, and it’s easier just to leave it” P7

“More so in the public health service, there is maybe less empathy for patients”.

Two participants reported that doctors are not adequately fulfilling administrative tasks relating to patient care. They stated that doctors refer PC patients too late, are not completing the necessary documentation on time, and, when completing forms, they are doing so incorrectly.

“The present challenges are very much in dealing with doctors who don’t know how to write down analgesia, or doctors who have forgotten how to fill in forms” P2

A few participants reported challenges related to nursing staff. One participant stated that some nurses are not aware of PC principles; and that this is seen in their patient care which does not respect the patient’s dignity.

“In the wards itself, it’s also quite difficult, because you will come across some nursing staff who are not thinking in the same line as palliative care and for instance someone will be happy to restrain a patient, but they don’t find out what the cause of the patient needing to be restrained is. And I find that very important because someone could pass away two hours after being restrained and that is not a very dignified way to die” P2

Another participant referred to an incident which highlights nurses’ misconceptions about morphine.

“a patient who was actively dying and we started morphine infusions and we got a special infusion pump from hospice...and then there was a huge outcry from both the family and our nursing staff that they felt that we actually from euthanasia and there are such misconceptions about giving someone who is in pain, morphine” P15

Three participants reported that the hierarchical structures in the hospital affect the nurse’s ability to practice PC adequately. One participant stated that because of hierarchy she lacks authority which prohibits the adequate provision of PC.

“For now if I want to do anything to the programme I must still report to someone. I feel if more authority is been given to me to put in place certain things and to say to certain people, give certain instructions to certain people, but now I can’t speak, I am just a sister. They will not listen to me, they will listen to the person higher than me... even doctors you understand, they don’t listen to nurses” P9

One participant reported that nurses do not complete administrative tasks adequately.

“I find that the note taking on the nurses’ side is not always adequate. I can look up things afterwards and not find any information about bedsores for instance, when in actual fact I’ve known that they’ve had bedsores. I can possible also come across somebody who is concerned about the patient because they know they have fallen, but there is no note made of that” P2

4.6.5 Patient, Family and Community Factors

Patients not being adequately cared for at home was raised as a prohibiting factor by several participants. A few participants stated that this was because families can’t look after patients, families fear death, or because the patient lives alone and cannot care for him/herself, or because the patient is homeless.

“the family issues that we need to sort out and families that can’t look after patients” P9

Some participants stated that it is because of poverty and families not having resources that there is inadequate care at home while another reported that pure neglect of abuse is a reason for inadequate care at home.

“A lot of patients that require palliative care come from a very poor socio-economic background” P11

“We have some very sad cases that come back with back sores and things because they were not being taken care of properly, people just get their grants” P12

One participant reported on the misconceptions of PC and Hospice that some families have.

“families need to be educated and communities need to be educated because what I have found out here in the ward also or even the reports that we sometimes get is that people, some of them are very reluctant to have their people under hospice because when we make the referrals, we find out that they have been informed that once the person is referred to hospice then that one is going to die” P12

Health care providers and service users’ different views on where someone should die has posed a challenge.

“The public feel that this is a place to die, and we feel the opposite, and so there is a bit of conflict there” P15

One participant reported that patient can be reluctant to take medication.

“some patients are reluctant medication users” P13

One participant identified family dynamics as a prohibiting factor.

“families that don’t speak to each other and the dynamics and things like that are challenges for us” P9

4.6.6 Policy Factors

A few participants expressed their frustration with policies that are created but are either not implemented or not realistic in terms of implementation.

“National implements policies, but they don’t consider really the implications” P5

“things look nice on paper, but that’s where it ends because there is not enough follow-through of what gets implemented” P17

One participant stated that without having policies that support PC in the Hospitals, people are not pushed to practice it.

“Not everybody likes palliative care, and I think we will need to have a mind shift because like you say, if the policy come into, if they implement the palliative care policy, then you don’t have a choice, it’s not if you like it or not, you have to do it” P16

One participant gave examples of how bureaucracy has been a prohibiting factor in developing PC.

“we have become quite a bureaucratic managerial system...and managers are very heavily influenced by policies, so if there is no policy of palliative care, then there’s no need for me to shift money for this and they’re just not going to do it no matter what you say” P7

4.7 THEME THREE: RECOMMENDATIONS FOR INTEGRATING PALLIATIVE CARE

Participants’ recommendations regarding integrating PC will be presented within the following six subthemes: Acknowledgement of the need for raising awareness; programme development; adequate resources; education and training in PC; networking and building partnerships; and policy recommendations.

4.7.1 Acknowledgement of the Need for Raising Awareness of Palliative Care

A few participants highlighted the importance of acknowledging the need for PC which linked to the importance of raising awareness about PC.

“We’ve got to recognise that palliative care is as important as the other fields...You need to know that you need it” P4

Recommendations for raising awareness was offered by several participants and included: Using tools or methods to help identify PC patients in the hospital; discussing PC is morbidity and mortality (M&M) meetings; and keeping health care providers updated as to what happens to their PC patients.

“A referral sheet works very well in a hospital as a trigger” P7

“you can also just have a once a month sort of a M&M on a hospice or on palliative care patient to inform everybody that this is the patient, and this is what happened and this was the management” P16

“I think it’s also our responsibility as the palliative care team to keep them updated...because if you know what happens with a patient then probably next time you are probably going to be more aware” P16

Some participants recommended that PC be seen as continuity of care. The following participant argued that one needs to ensure that PC is seen as a normal part of medicine, rather than additional work.

“palliative care must be seen as the continuity of care. It should not be seen as a different and a new service. It is the natural next step” P3

Another participant said that PC should be approached horizontally rather than vertically, and that PC be made everyone’s business.

“Palliative care shouldn’t be a vertical programme or a vertical service. Palliative care should be applied anywhere in the hospital...palliative care is everyone’s business...It shouldn’t also be dependent on certain individuals, because that person might decide to leave, then you sit with a gap” P5

A few participants recommended getting staff and management buy-in.

“you need to start from the top down approach. If you don’t get your managers involved it will not work” P6

4.7.2 Programme Development

When discussing programme development, a few participants recommended that one aims towards integration rather than addition. Seeing PC as a normal part of medicine was considered important in this respect.

“If the patient has been identified as a patient within the palliative care group, you should have the same management and the staff managing those clients must have the same awareness and the same training, so that there’s consistency across the board” P5

“It needs to be very integrated in your system, so it doesn’t feel like an extra chore or an extra task” P15

One participant recommends tailoring the programme to suit the institution.

“you’ve got to do what works for you. So, you’ve got to customise it to what works for your organisation” P17

One participant explained how you just need to start somewhere.

“there is actually too much to do so we must just start somewhere and even if it is small, I mean if it is a short counselling session or a short information session on something like pain management or just information on this service and so we have to start somewhere” P16

One participant reiterates that one can find a way to create a programme, regardless of circumstances.

“It’s really very tough right now, but we mustn’t give up. We must work within the context that we have. If we recognise that palliative care is important, if we know that it works, if we see its value, then we must find a way to create some sort of programme within our hospital, and you can with not too many resources” P4

A few participants recommended that to get buy-in, one needs to that PC achieves better outcomes. Conducting research, capturing data, and obtaining statistics was recommended.

“in terms of getting over the challenges of getting the buy-in of management, research is key. When you can prove through your work that you can show evidence that you are achieving better outcomes, cost saving, and improving quality of care, then it’s hard to actually challenge that” P3

4.7.3 Adequate Resources

All participants provided recommendations regarding staffing. Identifying a champion to drive the programme was recommended by many participants.

“you just need one champion...you can have a social worker, you can have a nurse, you can have a bed manager, you can have a doctor, you can have a speech therapist, but you just need someone to start the conversation” P8

Some participants recommended specific characteristics for champions. A few participants stated that they must have knowledge of PC and clinical work.

Must have knowledge about PC: “It does not have to be a doctor, it can be a social worker, it can be an OT, it can be a nurse, but you must have knowledge about palliative care” P5

A few participants recommended that one should identify people with an interest and passion for PC.

“You just have to find the person that is able to take it on, but if they don’t have an interest in it, then you’re bound to fail” P17

“if you do palliative care, you must be really able to go that extra mile for people, and have passion” P9

A few participants referred to the need for resilience.

“you do need to be able to be resilient to hear a lot of negativity towards palliative care at first. It is something that takes a long time, so you’ve got to be resilient in that” P6

A few participants recommended that the champion be in a senior or management position.

“the more senior the person is, the further it goes...whether a senior nursing sister, senior social worker, senior doctor” P6

A couple of participants recommended that the champion be present in the hospital.

“There needs to be a champion who is going to be in the hospital for a long period. I think you need a minimum plan of at least five years” P3

“You’ve got to be present so that you always put your hand up even if you make your name aapie, you’ve got to put your name up and say but doesn’t this patient actually require palliative care?” P6

One participant recommended that the champion have a trust link with staff in the hospital.

“if they just see you as another person and they don’t believe in your abilities or your effectiveness or that sort of thing...they need to know that you are going to add value to them and not just create more work for them” P13

One participant recommended that a champion not have a divided focus.

“If you have one leg in this sphere, and your other leg in this sphere, then you have divided attentions. So, then that means later on you don’t know where your allegiances really lie. Is it with clinical work, or is it with the palliative care?” P5

Some participants recommended a multidisciplinary approach to PC services in the hospital and that a PC team be formalised to ensure sustainability.

“is not just one person that can manage a patient, it must be a whole team to make a difference and to make the programme work” P1

“they would need to formalise a palliative care team because you know so often in state sectors, the intention is there but due to work constraints these things often fall apart” P11

Specific disciplines or professions to form part of the team were recommended by many participants. Most of these participants recommended a registered nurse before any other professional, followed by a social worker.

“definitely appoint a nursing person as a palliative care nurse, and then work from there” P17

“you will need your social worker and it doesn’t matter whether it is the community social worker and so on, you need the social” P12

A doctor was the next professional recommended.

“services can even improve if there is a dedicated doctor who can do that so that the forms are not lying there for two or three days” P9

A few participants recommended spiritual advisors or carers to form part of the team.

“I think a spiritual advisor is also beneficial to have on the team, I wouldn’t say it is critical but definitely beneficial” P11

Two participants recommended recruiting volunteers.

“we probably wouldn’t function so well without our volunteers” P2

One participant recommended an office manager or administrative officer for PC.

“I do think they possibly need an office manager sort of individual that can run the service and do the admin stuff, so that the clinicians can stick to the strict clinical work” P4

Other participants recommended a pharmacist, community care worker, dietician, and occupational therapist to be in the team.

“there is always a role for a pharmacist, you know, they often do not get included in these teams, but I think it is important in terms of pain control” P11.

“those people that are quite knowledgeable about their community, they know exactly who lives where and what going on where” P16

To ensure sustainability of the PC programme appointing permanent staff was recommended by one person.

“it must be sustainable and to make it sustainable you need to appoint people as permanent staff”

P17

It was recommended by one participant that only certain staff need to be available for PC all the time while others can be consulted when necessary.

“you must have people that are always there that know what to do, but as a skilled person like a doctor or a social worker, you just need to go and see if things are still going smoothly” P12

One participant recommended that PC be made a priority through making it part of staff’s job description.

“it needs to be their job description to set up, manage and run palliative care services in the hospital and bring this group of people together...they need to have their calendars cleared of other stuff, so they can actually do it” P7

Staff support was recommended by a few participants. Some of these participants highlighted the importance of looking after your staff to run a PC programme effectively.

“It’s not a once off thing...you need to constantly see if everybody is still mentally healthy and if they are supported and are they motivated still because it can very quickly and eventually turn into an extractive set up where you are relying on those staff members to be constantly giving energy” P10

Access to debriefing was recommended by a few participants, as well as promoting self-care.

“The passion needs to be supported and therein lies a lot of debriefing” P10

“If your spiritual foundation is not set then you don’t know where you are coming from or where you are going to” P9

Having appropriate infrastructure and material resources, including drugs, was recommended.

“when you start, you first put your things in place, you know, stationary is important because you must capture data, an office, a family room where you can have family meetings, small things but it’s so important” P9

Acknowledging the need for more intermediate care facilities was recommended by another participant.

“I would like to see, and not just for our hospital, but for the Western Cape, is we have to have more access to these things otherwise we’re going to sit in a situation like in Gauteng where facilities close and we don’t have anywhere to go with these patients” P15

Acknowledging challenges related to funding, a few participants recommended ways of working around budget constraints by reducing waste in the system and using existing resources and services rather than creating new services.

“Every health care facility in the country is facing budget constraints. So, we can’t ask for money to implement a new service. So, we have to just train everybody who is currently there, and we need to infuse palliative care into the current system” P3

“there’s lots of waste, there always is. These are little things. When you are willing to save on electricity, when you are willing to save on paper, when every little cent matters, then you create a little pot, and that little pot eventually gives you the leverage to hire someone” P4

A few participants recommended drawing on community-based services to reduce costs.

“I think what would help is integration with existing services, and that interestingly enough does not require more money. It just requires greater integration with community-based services” P4

While a few participants recommended ways of working around budget constraints, some suggested that one can find funding or shift funding for PC.

“Generally, in government all nursing posts aren’t full...there is actually money available so if you could persuade people to move it in one direction then you could create a nursing post” P7

“For the conditional grants and in order to qualify to apply for something, you need a structure, and who would be the custodian and then we actually have a team that we have identified” P10

4.7.4 Education and Training in Palliative Care

Almost all participants recommended sending staff on formal PC training including workshops.

“Equip them with the information and see how getting those skills would improve the scope of what they are doing already” P10

“they need the palliative care training so that they understand the holistic approach” P13

Informal training in the form of Teaching PC on academic ward rounds, as well as including Hospice members on the ward round for training purposes was recommended by a few participants.

“I would recommend ward rounds so that palliative care patients are identified” P13

“the ward rounds were completely developed for a different reason and then we decided just to attach hospice to it and it made all the difference and it’s not labour intensive, it wasn’t difficult to organise and it doesn’t cost a cent and so it is such a small and easy intervention and that for me I think is really at the heart of it” P15

A few participants recommended educating patients, families and communities about PC. One participant recommended education to demystify misconceptions about PC in the community while another participant recommended PC education to support families and prevent unnecessary hospital admissions.

“We need to educate them to understand that hospice is for palliative care and when you are on palliative care, it doesn’t mean the next day you are going to die, you can recover from being under palliative care a little bit. The limb that you were not able to use then, it gains a little bit of movement through palliative care” P12

“I think the community must know palliative care is actually something that happens in the community and not in hospital. So if the community can be trained or educated to know that a palliative care patient doesn’t need to be rushed to hospital at three o clock at night” P16

Educating patients, families and communities before and during programme development was also recommended by one participant to ensure community understanding and buy-in.

“So when the patient’s almost died, they rush the patient to hospital, so the patient dies in hospital. And now suddenly that hospital is going to have a change of approach which says hold it, we want your family member to have a choice, and if the family member chooses to die at home, the patient must go die at home. Now the community may stand up and say hey, the hospital doesn’t care anymore, they’re chasing the people home to die. So before you start introducing that, you better have had a conversation with them to say that were going to do that, so there’s no misconception of what you are actually doing” P3

4.7.5 Networking and Building Partnerships

A few participants recommended forming partnerships with community-based services.

“If you want it to be cost effective or a cost saving service, you have to have the link to prevent the frequent admissions and to shorten length of stay...for a palliative care programme to work effectively, you have to have both the community and hospital-based services” P13

One participant recommended having Hospice involved in the hospital PC programme as much as possible.

“having them on the platforms and having agenda items where they can speak and for us really the most important thing is having them on the ward rounds” P15

Some participants recommended learning from other people in the field who have knowledge or experience in PC hospital programmes.

“visit hospitals where it is established to see what you can learn from others, and how they can assist you” P17

A few participants recommended the promotion of continuity of care within the hospital, as well as across the different levels of health care.

“Provide the continuity so that if the patient comes back to the hospital again, there is sort of one person or one team that knows him and not to start the whole process from the beginning again” P16

4.7.6 Policy Recommendations

Promoting PC in policy making was recommended by a few participants.

“I think it is very important to have a policy that at least tells people you need to move in this direction” P7

One participant recommended developing PC policies for one's own hospital.

“I think there are a few documents of which the policy is there, of which a training policy is there, and of course things like drug availability, all of those things should be there, yes. And there should be other palliative care policies within the hospital, like an end of life policy and things like that” P6

One participant recommended advocacy for PC to be implemented in other hospitals.

“there should be more palliative care models in other hospitals. Because I think if everyone has a palliative care branch, it strengthens the idea and the understanding of palliative care....And if we have that then palliative care starts to become seen as an equal partner” P4

Another participant recommended that policies promote PC growth at a community level to support PC in the hospitals.

“the growth needs to be at a community level” P17

4.8 CONCLUSION

This chapter presented the study’s findings which were grouped into four main themes and various subthemes. Enabling factors were identified, namely: Awareness of PC needs and benefits; resources, education and training in PC; support structures; and partnerships and community-based support. Prohibiting factors were identified, namely: Hospital culture; resource challenges; education and training challenges; challenges relating to health care providers; patient, family and community factors; and policy factors. Participants’ recommendations were related to raising awareness; programme development; adequate resources; education and training in PC; networking and building partnerships; and policy recommendations. Although a comparative analysis was not conducted, the emerging themes tended to reflect agreement across professions.

In the next chapter, these themes and subthemes will be discussed in greater detail with reference to literature.

CHAPTER 5: DISCUSSION

5.1 INTRODUCTION

This chapter provides a discussion on the key factors which were identified as either promoting or inhibiting integration of PC in a hospital setting. Key issues emerging within and across these areas will be discussed in relation to relative policy frameworks that support PC development. These include the WHO PHS and the NPFSPC frameworks, which both advocate policy support, availability of essential medications, education and training in PC, and effective implementation of PC at all levels of care.

5.2 LEADERSHIP, GOVERNANCE AND POLICY

Strengthening leadership, governance and policy that supports PC are key components proposed in the WHO PHS and in the NPFSPC. Leadership and governance has been identified as a fundamental component for the implementation of PC in this study and supported by other studies conducted by Sommerbakk et al.,⁴¹ Spaulding et al.,⁵² Kalies et al.,²⁷ and Smith et al.⁴⁴ Key factors emerging within this category relate to PC champions, support systems for PC, and the need for PC policies.

5.2.1 Palliative Care Champions

Findings from the current study highlighted both promoting and prohibiting factors relating to the presence of champions. Howell and Higgins define champions as: “individuals who emerge to take creative ideas (which they may or may not have generated) and bring them to life. They make a decisive contribution to the innovation process by actively and enthusiastically promoting the innovation, building support, overcoming resistance, and ensuring that the innovation is implemented”.^{63(p.40)}

This study strongly emphasises the presence of champions as an enabler in the integration of PC and highlights the importance of PC champions in the integration of PC. Participants stress the need for such champions to have an interest in, and a passion for their role in PC. Similarly to the description of champions provided by Howell and Higgins,⁶³ champions were referred to as having specific qualities, knowledge, skills, and influence. However, the current study’s findings differ from Howell and Higgins’s study in that the need for passion as a personal quality is repeatedly emphasised as a fundamental enabler.

Howell and Higgins⁶³ identified that certain personality traits (confidence, perseverance, enthusiastic), ability to lead (vision, execute plans, capacitate and recognise others), and experience in the specified field and organisation (reflecting knowledge, competence and authority) were key to a champion’s success.⁶³

Other literature also supports the concept of PC champions as an enabling factor, including studies conducted by Sommerbakk et al.,⁴¹ Ntizimira et al.,⁵¹ and Gwyther et al.³⁷ Although Sommerbakk et al.⁴¹ state the need for champions, and the importance of choosing the right people to be champions, they suggest that it is not vital for these people to be interested in PC, and that choosing those who are less interested could be a strategy to prevent potential obstructions. This is different from the current study that emphasises the need for champions to have interest in and passion for PC, suggesting the potential need for champions to identify themselves. Interestingly, Sommerbakk et al.⁴¹ suggest that the presence of champions could be used as a strategy for integrating PC into hospitals. However, a study conducted by Witkamp et al.⁶⁴ to assess the impact of a network of PC nurse champions as a strategy to improve care in the hospital, did not produce clear results as to whether the strategy of “champions” was effective. Individual factors (such a knowledge and skills) pertaining to the different champions made it difficult to assess the strategy itself.

It is clear from the above discussion that both the findings of the current study and other relevant literature highlight the importance of champions to advocate for and facilitate PC programme development in health settings. However, one potential challenge linked to this argument is that, if one relies on champions, sustainability could be endangered because it would entail relying on individuals with particular personality traits, which is hard to measure, as noted by Witkamp et al.⁶⁴ This highlights the need for support from both hospital management and broader government structures, so that programmes do not rely solely on characteristics of certain individuals. Policy development and implementation is a crucial enabling factor in this regard.²⁹

5.2.2 Adequate Support Systems

Adequate support systems for the purpose of this discussion refers to support provided at different levels in the system including personal/interpersonal support, administrative support, and management support of PC integration. In the current study, this included having support for PC built into job descriptions to ensure that PC tasks are prioritised and followed through accordingly. In addition, provision of therapeutic support to service providers was a further area of support need identified, linked to the emotional labour involved in PC. Support from hospital management was also noted, including shifting posts to accommodate PC, and good communication channels within the hospital organisation. At government level, support was discussed as direct interest and commitment to PC, including the development of policies that promote PC integration.

This study highlights the important role that leadership and governance (at organisational and Departmental levels) plays in providing an enabling environment that supports PC in hospitals. In the hospital or organisational level this includes drawing on and supporting individual champions (discussed earlier) and other individuals and teams that provide PC; providing an enabling organisational culture that values PC as an important part of health care; interpersonal and organisational communication processes and structures that support PC; and ensuring that the necessary resources and administrative support are provided to support PC. At Departmental (district, provincial and national) levels, this support needs to be expressed through the development of relevant policy and legislation, realistic and effective implementation of the policies concerned, and budgetary support, discussed below.

Leaders who ensure that necessary systems are in place, reflect transparency, institutionalise good communication, foster participation, and make PC everyone's business were identified as enablers in this research as well as by Sommerbakk et al.⁴¹ This includes recognising that the lack of nursing representation in management constitutes a barrier to integration of PC in hospital settings.

The findings from this research also support Sommerbakk et al.'s⁴¹ conclusions that a hospital culture that reflects norms and values that include negative attitudes and beliefs about PC; resistance to change; and lack of administrative and management support has been noted as prohibiting factors. Sommerbakk et al.⁴¹ suggest that a barrier to change in an organisation is the staff's lack of understanding and support for those conducting extra activities resulting from needed change.

4.2.3 Enabling Policy

As outlined in Chapter one, the WHO PHS emphasises policy support as a priority. The South African NPFSPC represents a framework that aims to address identified challenges and highlights one of its goals as strengthening leadership and governance to enable policy implementation.³⁰ Participants in this study suggested that the South African NPFSPC was a good step in integrating PC into the health system. However, it was also reported that there was still a lack of policies to support PC integration into hospitals, and that policy implementation challenges included constraints linked to bureaucratic processes. However, the participants in this study did not differentiate between district, provincial and national policies in this regard.

Policy support was also identified by Sommerbakk et al.,⁴¹ Spaulding et al.,⁵² and Kalies et al.²⁷ as being crucial to supporting the change needed to promote integration of PC in the organisation. Sommerbakk et al.⁴¹ support the findings from the current study, suggesting that a barrier to PC integration is a lack

of, or inadequate policy support to promote and support PC trained individuals in facilities. It is important to note that Spaulding et al.⁵² argue that success of programmes is dependent on policies being tailored to specific organisations and socio-economic contexts. This suggests the importance of a needs assessment prior to programme development to ensure that both policies and their implementation are ‘grounded’ in the realities of the local context. The current study highlighted that the three participating hospitals, although in the same province, tailored their PC programmes to meet specific local needs and realities. For example, one of the hospital’s PC programme reflected a stronger community engagement orientation because of their location and established community partnerships.

Kalies et al.²⁷ support this point and further recommend that policies are developed transparently, using an interdisciplinary approach that includes experts in PC (knowledge and practice), and allowing for flexibility to be developed in the different phases of implementation. What is interesting to note is that in the Western Cape, a task team of professionals in the field have recently developed a proposed model for the implementation of the PC policy in the Western Cape³¹. This implementation plan reflects all the recommendations provided by the current study and Kalies et.al.²⁷ However, when looking at the PC policy, it is clear that implementation requires an appropriate funding for its goals to be achieved. This poses a number of challenges linked to material and human resources, particularly in a context such as South Africa, where no financial resources have been allocated for PC integration. At the recent launch of the NPFSPC in Cape Town (29 October 2018) the Western Cape Minister of Health clearly stated that there will be no funds allocated to the development of PC services in the Western Cape and urged service providers to make use of existing resources.

Many of this study’s findings and literature supported the areas identified in the WHO PHS framework. However, it interesting to note that some areas highlighted are NOT currently included or emphasised in the WHO PHS framework. In the category of implementation in the WHO PHS, areas that are not overtly identified as crucial to integrating PC, and were considered crucial in this study, include partnerships with community-based organisations, direct leadership and management support of PC, and patient, family and cultural factors. Although the WHO PHS is a useful framework which can support the integration of PC in hospital settings, future policies and strategies may require review with regards to the factors influencing integration of PC in different contexts which would necessitate collaboration of all role players.

5.3 LACK OF RESOURCES

A lack of material (including infrastructure and facilities), financial and human resources were identified as a major barrier for integrating PC in this research and in other studies conducted by Sommerbakk et al.,⁴¹ Elsayem et al.,⁶⁵ Lamba et al.,⁴⁸ Beckstrand et al.,⁵⁰ Cornetta et al.,⁴³ Tapela et al.,⁵³ Aslakson et al.,⁴² and De Kort-Verhoef et al.⁴⁶

5.3.1 Infrastructure and Access to Medication

This study highlighted several prohibiting factors linked to infrastructure (structures and facilities in the hospital available for, or conducive to PC). This included limited private areas for patients and families to be counselled or to be alone with their loved one, and a lack of designated space and facilities for PC staff. Designated spaces and facilities for PC staff was noted as an enabler for integrating PC as it provides value and ownership. However, this may increase the development or view of PC being a “separate service”, highlighting an important debate around integration, discussed later in this chapter. Challenges relating to infrastructure and space were also identified as by Sommerbakk et al.,⁴¹ Elsayem et al.,⁶⁵ Lamba et al.,⁴⁸ and Beckstrand et al.,⁵⁰ with greater emphasis being placed on the Emergency Department which is considered to be the most challenging environment in this regard.

Access to essential medications for PC is highlighted as a fundamental component in the effective implementation of PC in both the WHO PHS and the NPFSPC. Access to medication emerges as a ‘resource’ factor in the integration of PC in some of the literature reviewed, with Cornetta et al.’s⁴³ study in Kenya, and Tapela et al.’s⁵³ study in Rwanda identifying lack of access to and cost of medication and resources as a key barrier, particularly in developing countries. However, it is interesting to note that only one participant from the current research highlighted access to medication as an issue, which may be an indication of how far SA has developed in terms of PC, and/or that essential PC medications are already a part of the South African essential drug list for general care.

5.3.2 Financial Resources

The NPFSPC highlights that because PC has not been considered a formal service model in South Africa, it has not been allocated the necessary funding. Yet, for this policy framework to be successfully implemented it would need funding to achieve its intended goals. The National Health Insurance (NHI) policy⁶⁶ does refer to a funding mechanism that ought to enable delivery of services and ensure access to PC in the packages of care at primary health care, district hospital and tertiary hospital levels, therefore funding should be appropriately allocated in the future.

Financial resources, regardless of where the funds come from, were reported as an important factor in the successful integration of PC by many participants in this study and other literature. Most participants in this research highlighted the need for appropriate financial resources for a PC programme to run effectively. A lack of funding for PC, economic challenges, budget reductions and fundraising challenges were specific prohibiting factors reported. Despite these challenges, it is interesting to note that the three hospitals in this study have used minimal governmental funding and used existing resources in creative ways to provide a PC service. This suggests that despite difficulties relating to funding, initiatives have still been successfully pursued. However, sustainability of these initiatives remains a challenge.

5.3.3 Human Resources

An inadequate health workforce to implement PC is clearly noted in and considered an essential area to address in the NPFSPC. However, this would require more staff, and training of staff, which would require appropriate funding allocation as described above.

When it comes to human resources, inadequate staffing in general, lack of dedicated PC staff, and insufficient time for PC linked to these shortages, were noted as major barriers in this study, and also noted in the studies conducted by Sommerbakk et al.,⁴¹ Beckstrand et al.,⁵⁰ and Lamba et al.⁴⁸ These challenges are not unique to PC, as new services are generally viewed as extra work rather than as a relief within an already over-loaded system. Although new services are often aimed at improving efficiency of services in the long-run, the integration and start-up process of such initiatives has the potential to be seen as more work. PC is often considered to be more time-consuming, given the comprehensive assessments and interventions that are required.

Although the findings from this research and other studies repeatedly suggest “lack of resources” as a major prohibiting factor in effectively integrating PC, the findings from the study conducted by Spaulding et al.⁵² suggest that if PC programmes have been developed on strong evidence and based on the needs of the specific organisation and socio-economic context, hospital resources can be used more appropriately and, in turn, decrease financial burden.

5.4 HEALTH CARE PROVIDER FACTORS

The WHO PHS and the NPFSPC support health care provider factors in that they highlight the need for, and promote the development of, PC knowledge and skills of health care professionals, in turn addressing some of the factors identified. This section discusses factors related to health care providers emerging

from the current study, including working in a context of loss, PC knowledge and skills, hierarchical systems and teamwork.

5.4.1 Working in a Context of Loss

Given that PC requires time, and that the health care providers concerned are continually faced with grief and loss, individuals involved in PC are at risk of burnout. Personal support was noted in this study as being important yet lacking. If PC were to be everyone's business and there was a commitment to teamwork and increasing the pool of expertise to support this, this barrier could be addressed (discussed below). What was interesting in the current study was that while one participant acknowledged that staff in that hospital were at risk of burnout, s/he added that burnout was actually an enabler of PC integration because it indicated the need for education and training in PC. This highlights that people are often placed under a great deal of pressure before the need is identified and help provided. While change is often needs-driven, it does raise the question of whether one should just respond to emergencies (a reactive approach), or place more emphasis on planning, preparing and implementing initiatives to prevent the challenges from occurring (a proactive and preventative approach). While it may seem ideal to be proactive, the reality seems to be that change is only initiated when needs are felt and expressed strongly enough.

5.4.2 Palliative Care Knowledge and Skills

Other challenges relating to health care providers which have been identified in this study, and supported by literature, include doctors' (and in some cases, nurses') lack of PC awareness, over-focus on a curative approach, pursuing futile interventions, poor communication and empathy skills, difficulty with role shifting, and limited beliefs and attitudes towards PC.

The tendency of doctors to pursue "cure" emerged as an important finding, as did limiting beliefs and attitudes towards PC. This raises the need for awareness raising and paradigm shifting which needs to be fostered in medical education as well as in the way leadership and governance of PC is implemented in hospital and other health settings. This includes addressing time-constraints linked to the level of care required for PC patients, as well as symptom management.

Difficulties relating to communication also emerged as a major factor in this study, supported by many other studies conducted by Cornetta et al.,⁴³ Aslakson et al.,⁴² Smith et al.,⁴⁴ De Kort-Verhoef et al.,⁴⁶ and Ganca et al.⁴⁷ These challenges related mainly to breaking bad news to patients and family members.

The difficulty in role shifting referred to above links to challenges health personnel experience when working in teams. This includes overlapping roles and therefore concerns relating to boundaries or professional territories, and the inevitable risk of conflict present in any group situation.⁶⁷

5.4.3 Hierarchical Systems

The literature reviewed in this study highlights factors relating to hierarchical systems preventing junior staff from practising PC, even if they have been equipped with the knowledge to do so. It is noteworthy, therefore, that the current study highlighted hierarchy between different levels of doctors, and between doctors and nurses as being a barrier for effective PC. Hierarchical issues in health care in general have been long-standing, with potential risks being highlighted, for example, in the Elaine Bromley case where a young woman died under the hands of two anaesthetists struggling with a task that two witnessing nurses could have managed but did not feel they had the authority to do so.⁶⁸ Although hierarchies are needed for accountability purposes, those less senior tend to avoid conflict by not challenging their seniors, nor “whistle-blowing” for the fear of their progress and development in the institution being compromised. Although not the solution on its own, Green et al.⁶⁸ suggest that an emphasis on teamwork is the way forward to ensure that decisions are not at the hand of only one person.⁶⁸

5.5 EDUCATION AND TRAINING IN PALLIATIVE CARE

Many of the factors discussed above, such as lack of PC awareness and knowledge and skills, are linked to a lack of education and training in PC. In the current study, provision of formal and informal education and training for service providers and for service users (patients and community) was noted as an enabler, with participants recommending academic ward rounds, attending conferences and workshops, and attending formal training as a means to educate staff. Integration of PC in hospitals requires an awareness of the needs and benefits, and an understanding and appreciation of the continuum of care. Although this study distinctly highlighted the need for education and training in PC, enough time and staffing to participate in education programmes is clearly required and appears to be a scarce resource. This challenge has also been noted by Sommerbakk et al.,⁴¹ Smith et al.,⁴⁴ and Aslakson et al.,⁴² and has been recognised as a barrier and hence a target for various policies that support the integration of PC.

Ensuring education and training in PC is identified as a goal in the WHA Resolution 67.19, the WHO PHS and the NPFSPC. The WHA’s Resolution 67.19 urging member states to integrate PC into their health systems recognises the need for basic, intermediate and specialist PC training, depending on the level of contact with patients in need of PC, and the complexity of care required. Similarly, the NPFSPC

highlights levels of PC expertise required by health care professionals, stating that those working at primary care level should have an understanding of the PC approach, those working at District and Regional levels should have general PC knowledge and skills, and those in specialist or tertiary hospitals should be trained as specialists in PC.³⁰

South Africa now has PC included in a few undergraduate medical degrees with the University of Cape Town and the University of Witwatersrand at the forefront of integrating PC in the medical education system. Besides including PC into these undergraduate degrees, the University of Cape Town now offers a post graduate diploma in PC as well as a Masters' programme. Other providers such as HPCA also offer various courses for health and allied health professionals. This growth shows an increasing appetite for PC education and training.

Although PC is receiving more focus in medical curricula now, it is of little use if the newly qualified health care professionals equipped with this knowledge do not feel that they can apply what they have learnt due to barriers created in the organisation, including dynamics relating to the hierarchy that exists between and across professions. Therefore, interventions that focus on health care providers already in the field, by means of mandating in-service education and training as a blanket approach (through policy and support at a governmental and organisational leadership level) may be one of the few ways to tackle limiting perceptions. Furthermore, increased PC expertise in health facilities is likely to facilitate the growth of PC champions, supporting the momentum of PC integration.

5.6 TEAMWORK, PARTNERSHIPS AND COMMUNITY-BASED SUPPORT

Teamwork has been noted as a fundamental component and enabling factor in the integration of PC in the literature and in this study. Participants from the three hospitals in the current study described “having a common goal”, “shared decision making”, and a “multidisciplinary approach” as being key aspects of the PC team. However, understandings of the term “team” differed across the hospital settings investigated, with special reference to who comprised the team. In one hospital the team members were all employed solely for the PC programme; in the other hospital the team comprised a combination of general staff and staff dedicated to PC; and in the last hospital team members comprised general staff and professionals from NGOs working in the community. These three different models included similar disciplines in their team; however, who they are employed by seems of little relevance. What appears relevant in all cases is that the patient receives the care needed, within the continuum of care framework. However, the one hospital appeared to draw and rely on partnerships and community-based support more than the others. This was noted as a definite strength of their programme.

This partnership approach is emphasised by the Health Research and Educational Trust who state that, “Each organization working independently toward its mission can have an impact, but by partnering with other organizations around a shared goal, the impact can be much greater.”^{69(p7)} In view of the growing demands on hospice services, new models of care are being explored. In a study conducted by Spencer,⁷⁰ a “patient-centric multi professional community approach” has been developed. This refers to a way of successfully working in partnership with statutory services to provide patient-centred care and prevent unnecessary hospital admissions, illustrating how the different structures and staff can work seamlessly together.

Hospital-community partnerships have become increasingly acknowledged for their joint efforts to address complex health system issues. Although hospitals are often conveniently located in the community and are considered to have knowledge and skills to improve health, the health system is too complex to be improved by one institution or sector single-handedly. Collaboration amongst allies in different sectors is seen as essential to optimally identify and address health needs and promote care on the continuum. Often, common challenges are shared by hospitals and community-based organisations, providing an opportunity for organisations to combine efforts and share expertise. This approach can decrease duplication of services, and in turn optimise resources.⁶⁹

This study highlighted the value of networking to build mutually beneficial partnerships and gain community-based support in the integration of PC in hospitals. This finding is supported by Sommerbakk et al.⁴¹ and Tapela et al.⁵³ who state how networking and building partnerships with government and NGOs is considered to be fundamental to implementing the continuum of care. Given that socio-economic factors such as homelessness were identified as barriers to providing PC, provision of community-based support was vital to address these factors.

What is interesting to note is that, in both the current research and other studies reviewed in this thesis, networking and building partnerships has only been identified as a promoting factor in the integration of PC, with no mention being made of how it could also be a prohibiting factor. This indicates the need for further research but suggests that the advantages of using this strategy are heavily weighted in comprehensive efforts to integrate PC within a continuum of care framework.

5.7 THE INTEGRATION DEBATE

‘Palliative care integration’ refers to an amalgamation of services. A detailed definition provided by the InSup-C project is as follows: “Integrated palliative care involves bringing together administrative,

organizational, clinical and service aspects in order to realize continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers, paid and unpaid.”^{71(p2)} In a hospital setting it would mean that the provision of palliative care be the responsibility of all staff, not merely palliative care specialists.⁶⁷

In this study, as in other studies reviewed, participants’ perceptions of the definition of PC integration seemed to differ. On the one hand participants emphasised the need to make PC everyone’s business (which constitutes a horizontal approach), yet on the other hand, there is an argument for dedicated material and human resources (a vertical approach). This suggests conflicting views on what PC integration means in the hospital context. This challenge was further highlighted in discussions around PC team members (who comprises the team/ dedicated people versus everyone being responsible for PC); infrastructure and facilities (shared areas and facilities versus separate areas and resources); and funding (state, NGO, and/or donations).

This debate on whether and how to integrate health initiatives or keep them separate to strengthen and maintain their identity has been a long-standing, worldwide debate, not only in health systems, but also other sectors such as education (e.g. building an inclusive education system). In a study conducted by Atun et al.,⁷² where a systemic review was conducted to examine the impact of both integrated and non-integrated health programmes, it was established that although they both appear to have their merits, few interventions were ever fully integrated, nor completely separate. Rather, in most cases both were present, and success of intervention was based on the negotiation of the tension between the two. As seen in the three hospitals involved in the current study, the balance of vertical and horizontal approaches differ, suggesting or supporting the idea that the tension needs to be creatively addressed, appropriate to local needs and realities.

The proposed policy for integrating PC in the Western Cape clearly calls for additional staff, trained in PC, as well as supporting current system development, suggesting the need to find the balance between horizontal and the vertical thrusts. This is laudable but constitutes a serious challenge for the leadership and governance of our health systems, as management structures need to reflect this intention. In a bureaucratic system that tends to favour vertical silos, extra effort must be made to work horizontally to promote the integration of PC and other health services.

5.8 LIMITATIONS AND STRENGTHS OF THE STUDY

The researcher is an employee at one of the research sites, with her own experiences and views about the challenges and enabling factors influencing PC integration. As indicated in Chapter three, potential bias emerging from this challenge was addressed in a number of ways.

Research participants who had a clinical practice component to their work were mainly situated in medical departments; therefore, the findings did not include the views of those working in emergency and surgical settings. Inclusion of other specialists may have generated other results. For example, research has identified the need for PC in emergency departments^{44,50} suggesting that inclusion of emergency health care providers in this study could have added further valuable insights. Furthermore, the participants were all health care providers, thus omitting the voices of patients and families in this study.

This study was small in scale. An expanded study including more hospitals in the province and even nationally would have provided a more comprehensive picture of the factors that influence PC integration.

Strengths of this study include the researcher's experience, knowledge and training in communication and interviewing skills (suitable for a qualitative approach) and PC. Despite the potential bias related to the researcher being employed at one of the research sites, the researcher's experience in this context could also be considered a strength, in that having a deeper understanding of the topic could have allowed for the researcher to elicit richer content. Various professionals at production and management levels were interviewed, which provided a picture of the enablers and challenges from different perspectives and obtained a broader/systemic view of the enablers and challenges concerned.

Another strength of this study is that five out of the 17 participants interviewed are currently part of the provincial PC task team, tasked to use their knowledge and skills gained in their organisations to assist in the growth of PC in the Western Cape. This makes them good key informants for the purpose of meeting objectives of this study.

5.9 SUMMARY AND CONCLUSION

The above factors focus on both 'people' and 'structures' and can be viewed through a systems or ecological framework (including individual, relationship, community and societal levels). This is important to note as it is congruent with a public health framework which emphasises the need for a holistic view and comprehensive strategies to deliver health care.

Factors relating to leadership and governance, resources for palliative care, education and training, and partnerships and community-based support all play a role in influencing integration of PC in the hospital setting. It appears that for PC to be successfully integrated appropriate governance and leadership is needed to advocate for and ensure that the necessary systems are in place, to provide the necessary resources, to promote PC education and training, and to build the necessary partnerships. However, for leaders to do this, they need to be PC conscious.

Where PC has been successfully provided, charismatic champions of PC have been identified as a promoting factor in the start and growth of PC services.⁶⁷ This study and literature suggests that PC champions and commitment from government structures is required for adequate and sustainable services, “Charisma continues to be necessary to prevent PC being strangled by over-rigid bureaucracy, but incorporation into existing health delivery systems is necessary to prevent it being stillborn through a lack of resources”.^{67(p.271)} This suggests that effective implementation is not only about ensuring the appropriate structures, but also about having certain types of personalities in the right positions to drive the process.

The term “continuum of care” was referred to frequently in this study. This highlights the awareness that care does not merely start and end in one place. One patient may require primary, secondary and home care, and visit a variety of facilities in the course of their illness. The health system in South Africa is made of various structures. It requires collaboration and cooperation from various governmental departments such as Health, Social Development, and Education, as well as community-based organisations for PC to be successfully integrated. The conversation of PC needs to be the same conversation spoken at all different levels of care and amongst various role players. The referral pathway highlighted in the NPFSPC provides a framework for promoting continuum of care in South Africa.³⁰

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1 INTRODUCTION

In response to the need for PC integration into the health system (including hospitals) in South Africa, the aim of this study was to identify factors that influence integration of PC in three state hospitals, and to provide implementation recommendations. In this chapter the researcher will draw conclusions from the findings in relation to the study objectives and provide recommendations for the future.

6.2 FINDINGS IN RELATION TO STUDY OBJECTIVES

Objective one was to describe existing services in three state hospitals in the Western Cape. Descriptions obtained included an account of the reasons for the PC programme development, infrastructure and funding available, the PC team composition, the coordinator, PC meetings, and in- and out-patient services. All three hospitals' programmes were developed from an identified need and all participants stated that PC is integrated into the hospital.

Objective two of this study was to identify prohibiting and promoting factors in the integration of PC in the three hospitals. Prohibiting factors identified most frequently related to human and material resource challenges. One striking finding was the importance of champions, considered to be a strategic factor to be considered in the integration of PC in hospitals in the literature. However, contrary to the literature reviewed, the characteristics of champions received particular attention in this study, including a call for passion for PC. Despite this emphasis, relying on individual characteristics of champions is not enough to ensure sustainability of a PC programme. It is clear that the leadership provided by individuals has to be balanced with organisational and departmental support to ensure sustainability.

While a 'lack of material and financial resources' was an important finding emerging from this study, and emphasised in the literature, it seems that this study's participants placed more emphasis on the role of people and agency in overcoming these constraints. This centers agency as a determining factor in the success of initiatives. This also emphasises the importance of creatively making use of existing resources to achieve one's goals, particularly in a resource challenged context such as South Africa.

Other prohibiting factors noted in the study related to the hospital culture, education and training, health care providers, as well as patient, family, community, and policy factors. Enabling factors identified included having adequate resources, awareness of PC needs and benefits, education and training in PC, support structures, partnerships, and community-based support.

The need for PC education and training has been strongly supported in this study and needs to be addressed at various hierarchical levels to ensure that those being equipped with the necessary PC knowledge and skills are supported to apply it. This suggests that careful thought and planning needs to go into how new knowledge and skills are introduced and implemented into existing systems. The use of innovative in-service initiatives is important in this regard. Networking and partnerships, including community partners was also highlighted as a major enabler in this study, highlighting the need for collaboration of teams in the hospitals, and effective partnerships with sectors in the community to ensure that PC is practiced along a continuum of care.

Objective three of the study focused on eliciting views on how challenges to integrating PC in a hospital setting could be addressed. Participants' recommendations most frequently related to ensuring adequate resources for PC, specifically human resources. This was closely followed by providing education and training in PC, networking and building partnerships. Other recommendations were related to raising awareness, programme development, and policy support.

The need for 'people' and 'structural' (at organisational and Departmental levels) support and development is emphasised in this study and literature. This highlights the need for an enabling policy, leadership and governance, well as the support of individuals and teams in the hospital system. When it comes to leadership and governance, challenges relating to integration emerged as an important finding in this study. The integration debate, which highlights the tension between developing specialist services versus making PC everyone's business, emphasizes that, while the needs and realities of local contexts should determine the way in which this tension should be addressed, a combination of specialist knowledge and skills with related generic competencies should be provided. This means that management structures need to include some form of horizontal thrust that informs the vertical structures reflected in organisations such as hospitals.

Although each hospital had a different model of PC, the same enabling and prohibiting factors were reported, and similar recommendations provided. The findings were well-supported by literature reviewed in this study.

6.3 RECOMMENDATIONS FOR THE FUTURE

Although valuable recommendations were provided by the research participants, the researcher provides recommendations based on this study's findings, other literature, as well as her own views on the topic.

With regards to practically integrating PC in state hospitals the following is recommended and presented in order of priority (although priorities for each Organisation may be determined by its unique context):

- 1) *Conduct a needs assessment:* An evaluation of needs assessment methods appropriate for South Africa is necessary. Various approaches to identify the need for PC services have been developed, implemented and evaluated. For example, studies conducted by Murtagh et al.,⁷³ Higginson et al.,⁷⁴ and Gomez-Betiste et al.,⁷⁵ refer to various methods. However, these studies were conducted in the UK, a context very different from South Africa. No one universal approach may fit every country, nor facility. Based on this study, it is recommended that specific facilities' readiness and needs for PC integration be assessed by performing a gap analysis (comparing one's own facility with a similar facility that has a PC service, as well as policy requirements); prioritising identified needs in relation to goals, certainties and limitations; gathering information on influencing factors from management and those in clinical roles; evaluating and providing feedback on the information; and developing an action plan.
- 2) *Raise PC awareness:* Ensure management is aware of and kept up-to-date regarding relevant policies and requirements, and benefits of being a part of this initiative. This could be pursued by making PC part of management, strategic planning and board member meeting agendas. Furthermore, make PC part of the hospital culture by organisational leaders role modeling and encouraging the values and norms underpinning PC practice. Increase knowledge and skills in the organisation by encouraging and supporting informal and formal training and introducing the conversation of PC into already existing academic ward rounds and meetings.
- 3) *Identify champions:* Identify individuals (from any discipline) with an interest in PC and ability to influence others, who will drive the programme, and include their PC role in their job description. Ensure that if they are not already knowledgeable about PC, opportunities are made for them to gain knowledge as soon as possible, including their knowledge of the most recent and relevant PC policies. Champions should familiarise themselves with and inform existing relevant PC policies in South Africa to ensure that the following recommendations can be pursued.
- 4) *Ensure adequate human and material resources:* Advocate for required resources (material, human and financial) as stipulated in current policies wherever strategically appropriate. One way of doing this is to access or to compile statistics that reveal the need for resources to support PC. However, it is also important to recycle, reduce waste and creatively use existing resources where possible. Principles of lean management could be applied to identify and reduce waste and improve efficiency.

5) *Network and build partnerships:* Build partnerships with hospitals with similar contexts who already have PC services. Visit those sites and meet with relevant key informants to learn from promising practices being implemented. Adopt and adapt strategies that could be applied in one's own context. Develop and nurture relationships with NGO's specializing in PC in the surrounding community for support and to ensure continuation of care. Request that NGO staff attend ward rounds and meetings in the hospital as a way of raising awareness of PC and strengthening the partnership, and hence the continuum of care.

The researcher recommends that further research on factors that influence integration of PC be conducted in tertiary and district hospitals, including health care professionals working in emergency care departments, patients and families so that their voices of the barriers experienced, and/or witnessed can be expressed and addressed. It is also recommended that similar research be conducted at a primary health level and in nursing care homes given that PC should be seen on the continuum of care. Further research on characteristics of champions is also recommended; including how their strengths can be optimally used.

In conclusion, although enabling policy and structures are needed to promote and support development, it is up to individuals to ensure that the needs, strengths and weaknesses of their specific organisation are identified and action plans implemented. The role of the personal agency in developing policy and creating structures in efforts to integrate PC in hospitals is therefore emphasised.

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APPENDIX A: HUMAN RESEARCH ETHICS COMMITTEE APPROVAL LETTER



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7921
Telephone [021] 406 6621
Email: shuretta.thomas@uct.ac.za

Website: www.health.uct.ac.za/fhs/research/humanethics/forms

20 July 2017

HREC REF: 475/2017

Ms Linda Ganca
Family Medicine
Falmouth Building

Dear Ms Ganca

PROJECT TITLE: FACTORS THAT INFLUENCE INTEGRATION OF PALLIATIVE CARE IN A STATE HOSPITAL (MASTERS CANDIDATE - MS R LAZARUS)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 July 2018.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval before the research may occur.

The HREC acknowledge that the student, Rebecca Lazarus will also be involved in this study.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical

HREC 475/2017

Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

APPENDIX B: INFORMED CONSENT FORM

Informed Consent Form

Part I: Information Sheet

Introduction

I am a qualified and practicing social worker, enrolled in a Masters Course in Palliative Medicine through the University of Cape Town. I am conducting a qualitative study that investigates factors that influence the integration of palliative care services in a state hospital. The National Department has released a National Policy Framework and Strategy on the Integration of Palliative Care, which will require all public health care facilities to implement palliative care services. You are invited to take part in the research study as you have been identified as a key informant in a facility that offers palliative care.

What is the purpose of the study?

This study seeks to explore palliative care services in three state hospitals; to identify factors that prohibit or promote integration of palliative care into hospital settings and to elicit views on how such challenges can be addressed with an intended outcome of making policy recommendations. The findings emerging from this study could provide useful insights and a roadmap to assist other hospitals and the South African health system on how to enhance the quality of care in their institutions.

Do I have to take part?

No, you do not have to take part. If you do agree to take part, you are free to withdraw from the interview at any time without giving us any reason. If you do agree to take part, you will be asked to sign a consent form, which shows that you have agreed to do so. You can take some time to think about whether you would like to take part.

What will happen if I take part?

An experienced researcher will interview you and ask you questions about the palliative care services in your institution. The interview may be scheduled in or after working hours (depending on your availability and preference) and will last approximately 30-60 minutes. With your permission, the interview will be recorded using a Dictaphone.

What are the benefits of the study?

There will be no direct benefit to you, but your participation will help the researcher to find out more about the influencing factors impacting on palliative care integration in hospital settings in order to assist government and other hospitals to develop appropriate programs.

Will I be remunerated for participating in the study?

You will not receive any compensation for participating in this study.

What are the risks of the study?

You may feel uncomfortable talking about some of the topics such as opinions of colleagues and government policies. You are encouraged to discuss these concerns with the researcher, but you are free to stop your participation at any time of the study at any time. Every effort will be made by the researcher to minimize your discomfort and to ensure confidentiality.

Will my taking part in this study be kept confidential?

Strict precautions will be taken to safeguard your personal information. The information that is gathered from the interview will be stored in locked cabinets, and digital information computer password protected. Only I and my supervisors will have access to the information. The data collected from the interview will be anonymous and confidential; your name will not be attached to the stored information nor used in any publications. Information obtained during the interview, which may reveal your identity, is confidential unless you agree to its release.

How will I know about the results of the study?

A summary of the research findings will be provided to each hospital. The final report will be submitted to the University of the Cape Town near the end of 2018, and can be made available to your organization if requested. The findings will also be shared with Hospice Palliative Care Association and the Department of Health and may be used in publications later.

Who can I contact if I have further queries regarding the study?

If you have any queries or concerns, you can discuss them now or later. If you wish to discuss them later, you can contact:

Rebecca Lazarus (Researcher)

Linda Ganca (Principle Investigator)

M: 074-1725353 W:074-1725353

W: 021-406 6590

Rebecca.Lazarus@westerncape.gov.za

linda.ganca@uct.ac.za

If you have any questions about your human rights or any ethical issues about the study, contact:

UCT Research Ethics Committee:

Mrs Lamees Emjedi

Research Ethics Committee

E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory

Telephone: 021 406 6338

Part II: Certificate of Consent

1. I have agreed to partake in a research study that aims to investigate the factors that influence the integration of palliative care in a state hospital.
2. I confirm that I have read and understand the information sheet and have had the opportunity to ask questions. Any questions I have asked have been answered to my satisfaction.
3. I have not been coerced into agreeing to partake in this study. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason.
4. I consent for the interview conducted with me to be digitally recorded.

Print Name of Participant_____

Signature of Participant_____

Date_____

Print name of Witness_____

Signature of Witness_____

Date_____

Statement by the researcher:

1. I have accurately presented or read out the information sheet to the potential participant, and to the best of my ability I have made sure that the participant has understood the information provided.
2. I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been voluntary.
3. A copy of the Informed Consent Form has been provided to the participant.

Print name of researcher_____

Signature of researcher_____

Date_____

APPENDIX C: SEMI-STRUCTURED INTERVIEW SCHEDULE

Semi-Structured Interview Schedule

Interview code No.:		Interviewer:		Length (mins)	
Date:		Time:		Venue:	
Participant details:					
Name:		Surname:		Title:	
Age:		Gender:		Qualification:	
Organisation:		Position:		Duration in organisation:	
Palliative care experience					

INTERVIEW QUESTIONS

1) Describe the palliative care services in this hospital?

- 1.1 How did they develop/come about?
- 1.2 Who makes up your palliative care team?
- 1.3 Describe your in-patient and out-patient services?

2) What factors have promoted or been helpful in the development and delivery of palliative care in this hospital?

- 2.1 Policies?
- 2.2 Organisational factors?
- 2.3 Personal or interpersonal factors?

3) What challenges have you, or the palliative care team encountered or are currently experiencing, in the development and delivery of palliative care services?

- 3.1 Starting the services?
- 3.2 Provision of services?
- 3.3 Policy challenges?
- 3.4 Organisational challenges?
- 3.5 Personal / interpersonal challenges?

4) How were these challenges overcome?

- 4.1 If they have not yet been overcome, how do you think they can be addressed?
- 4.2 Policy?
- 4.3 Organisational level?
- 4.4 At a personal/interpersonal level?

5) What do you believe is needed to improve palliative care services in this hospital?

- 5.1 What are your recommendations for other hospitals wanting to start or improve palliative care services?

6) Do you have any other comments regarding factors that influence integration of palliative care into a state hospital?

APPENDIX D: SUMMARY OF FINDINGS

Table X: Summary of Findings: Enabling Factors		F	%
4.3.1 Awareness of Palliative Care Needs and Benefits		12	71
	Realisation of the need and benefits of PC	7	41
	Attitudes and beliefs conducive to PC	3	18
	Seeing PC as a continuation of care	4	24
	Using practical methods of raising PC awareness	10	59
4.3.2 Human Resources		17	100
	Presence of programme leader	4	24
	Characteristics of PC champions	11	65
	Individual coping mechanisms	3	18
	Staff involvement	11	65
	Effective team work	12	71
4.3.3 Education and Training in Palliative Care		14	82
	Formal PC training for staff	14	82
	Conferences and symposiums	3	18
	PC discussions on academic ward rounds	4	24
	Inductions for new staff	1	6
	Patient, family and community education	2	12
	Staff burnout	1	6
4.3.4 Infrastructure and Material Resources		7	41
	Designated space for PC	6	35
	Facilities for PC	1	6
4.3.5 General Support Structures		7	41
	Having a support system is key	3	18
	Support from someone experienced in PC	2	12
	Access to therapeutic support / debriefing	2	12
	Support built into the job description	1	6
4.3.6 Management Support		14	82
	Support from the management team	13	76
	Shifting posts to accommodate PC	1	6
	Good communication channels	5	29
4.3.7 Government Support		4	24
	Interest and buy-in from Government	3	18
	Enabling National Policy	1	6
4.3.8 Financial Support		5	29
	Financial support is key	1	6
	Assistance from hospital management, hospital board & academic fund	3	18
	Conditional grant offered by District office and the Department of Health	2	12
	Donations	1	6
4.3.9 Partnerships and Community-Based Support		15	88
	Networking and partnerships	9	53
	Support from other organisations	12	71
	Community support	3	18
4.3.10 Other Enabling Factors		2	12
	Hospital culture conducive to PC	1	6
	Working in the context of a small community	1	6

Table X: Summary of Findings: Prohibiting Factors		F	%
4.4.1 Attitudes and Beliefs about PC		7	41
	Perceptions that PC is inferior to other services	5	29
	PC is viewed as a separate service / someone else's problem	5	29
4.4.2 Hospital Culture		10	59
	Rotating staff & students	6	35
	Resistance to change	3	18
	Lack of continuum of care	6	35
	Pressure for bed turn-over	2	12
4.4.3 Staffing / Human Resource Challenges		15	88
	Insufficient time for PC	10	59
	Staffing in the hospital	7	41
	Lack of staff dedicated to PC	10	59
	Emotional labour	4	24
	Volunteers requiring support	1	6
	Relying on individuals impacts on sustainability	1	6
4.4.4 Infrastructure and Material Resources		12	71
	Lack of resources for PC	6	35
	Limited private areas for PC	5	29
	Administrative burden	2	12
	Lack of supplies for PC office	1	6
	Insufficient access to medication	1	6
4.4.5 Lack of Funding		8	47
	Lack of funding for PC	6	35
	Economic challenges & budget reductions	2	12
	Funds not being allocated to PC	2	12
	Fundraising challenges	1	6
4.4.6 Lack of Support		4	24
	Lack of emotional support	1	6
	Lack of management support	3	18
4.4.7 General Training Challenges		10	59
	Lack of PC training	6	35
	Training costs	1	6
	Lack of time for training	2	12
4.4.8 Challenges Relating to Doctors		12	71
	Lack of PC knowledge / understanding	8	47
	Inadequate communication	4	24
	Over-focus on curative	3	18
	Pursuit of futile interventions	3	18
	Inadequate administration	2	12
	Lack of empathy	1	6
	Hierarchy preventing less senior staff practice PC	1	6
4.4.9 Challenges Relating to Nursing Staff		5	29
	Lack of PC knowledge / understanding	2	12
	Hierarchies and lack of authority impacting on practicing PC	3	18
	Inadequate administration	1	6
4.4.10 Patient, Family and Community Factors		7	41
	Inadequate care at home	6	35
	Lack of PC knowledge / understanding	1	6
	Homelessness	1	6
	Different views on place of death	1	6
	Patients reluctant to take medication	1	6
	Family dynamics	1	6

4.4.11 Policy Factors		6	35
	Policy implementation challenges	3	18
	Lack of policies to support PC in hospitals	1	6
	Bureaucracy	1	6
	Department of health not on same page	1	6

Table X: Summary of Finding: Recommendations

		F	%
4.5.1 Acknowledgement of the Need for Raising Awareness of PC		12	71
	Acknowledge the need for PC	3	18
	Raise awareness about PC	5	29
	See PC as continuity of care	5	29
	Get staff / management buy-in	4	24
	Show that management is serious about PC	1	6
4.5.2 Programme development		8	47
	Aim towards integration rather than addition	3	18
	Tailor the PC programme to suit your organisation	1	6
	Develop a process of identifying PC patients	1	6
	Prove that PC achieves better outcomes	3	18
	Start small	1	6
	Don't give up	1	6
4.5.3 Staffing		17	100
	Identify a champion to drive PC in the hospital	2	12
	Proposed characteristics of champions	8	47
	Adopt a multidisciplinary team approach	5	29
	Recruit people for PC & formalise a PC team	11	65
	Appoint permanent staff to ensure sustainability	1	6
	Ensure primary staff to be present all the time, while others overlook	1	6
	Make PC part of the job description	1	6
4.5.4 Education and Training in PC		14	82
	Offer formal PC training opportunities to staff	14	82
	Attend PC workshops	1	6
	Teach PC on academic ward rounds	2	12
	Educate patients / families / communities	4	24
4.5.5 Staff Support		4	24
	Look after your staff	3	18
	Ensure access to individual and group debriefing	4	24
	Promote self-care	1	6
4.5.6 Adequate Resources		7	41
	Infrastructure and material resources	1	6
	Ensure drug availability	1	6
	Acknowledge the need for more intermediate care facilities	1	6
	Work around budget constraints	2	12
	Use existing services / resources	3	18
	Access funding for PC	2	12
4.5.7 Networking and Building Partnerships		10	59
	Form partnerships with community-based services	4	24
	Learn from other people in the field	7	41
	Establish link with social workers at Day Hospitals	1	6
	Promote continuity of care	3	18
	Promote growth in community-based resources	1	6

4.5.8 Policy Recommendations		5	29
	Promote PC in policy making	3	18
	Develop PC Policies for your hospital	1	6
	Advocate for PC to be implemented in other hospitals	1	6
	Promote PC in primary health	1	6
	Promote PC growth at community level	1	6